

MEDICATION COMPLIANCE IN ASTHMATIC CHILDREN

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ABSTRACT

Medication compliance is of concern within all chronically ill populations. This is particularly so for paediatric asthma, where pharmacological intervention is the mainstay of therapy. The major difficulty is that parents of asthmatic children do not always administer the medications as prescribed by physicians. Findings to date suggest that asthma education programmes are an effective means of increasing medication compliance. Unfortunately, for the most part the literature has considered education information and compliance skills training to be part of the same package. The effect is that it is unclear whether results obtained to date are due to the education component, skills training or a combination of the both. The aim of the present study was to establish, from a confused literature, the relevant and comparative effects of compliance enhancing strategies with parents of asthmatic children.

Twenty-four parents of moderate-severe asthmatic children served as the subject population, participating in a group comparison treatment design with repeated measures. Daily recordings were gathered via self-recordings for medications administered, these were assessed by comparison to physicians' instructions. In addition, twice daily peak-flow recordings were obtained using a standard Wright mini peak-flow recorder. All other data was gathered by way of questionnaire. This data consisted of assessing (pre- and post-intervention) parental knowledge concerning asthma, parental Health Loci of Control and morbidity levels for each child. Measures were taken over four phases (baseline, intervention, six and twelve weeks post-intervention) and compared between groups to test for any significant change over time. Subjects were quasi-randomly assigned to one of four groups (N=6). The three experimental groups received instruction in either education information, compliance skills training or a combination package of these two. Material was presented within four 1-hour group teaching sessions. The fourth group (self-monitoring control) received no active intervention of any kind.

Results obtained indicate that there is no additional beneficial effect of education, compliance training or combination interventions over and above increases due to a self-monitoring effect with this population. All four groups within the study significantly increased their medication compliance levels post- intervention. Despite this, there was no significant increase in child pulmonary function as assessed by peak-flow readings. This suggests that increasing medication compliance above a certain level does not result in improved clinical outcome as measured by one aspect of pulmonary function

(peak-flow recordings). Hospitalizations and visits to the general practitioner for asthma were found to decrease significantly for all four groups post-intervention. The exact reasons for this are unclear; however, less use of medical care facilities is apparent. Finally a change in parents' perceptions of the controllability of asthma was recorded in the direction of uncontrollability.

Implications of the findings are discussed in terms of increasing medication compliance and future research.

1-1 ASTHMA - THE CONDITION

Although asthma is viewed by most as a contemporary affliction, it has actually been a problem for adults and children alike for centuries. Hippocrates (460-370 B.C.) was the earliest of medical people to refer to it, by describing the primary symptoms and associated wheezing (Mrazek, 1985). However the first detailed description was recorded in the second century by Aretaeus (Creer, 1982). He sketched in detail an asthmatic individual, providing descriptions of both the physical changes during an attack and the accompanying psychological states. Although asthma has affected so many through the centuries, two things continuously stand out; a) that it is of great concern to each time period and b) that despite good documentation, the underlying cause(s) remain a mystery. Rackemann wrote in 1918 that the fundamental disturbance of anatomy or physiology which expresses itself in attacks of asthma was unidentified (Creer, 1982). The truth is that asthma was and still is a threat to the lives of our children (Ellis, 1983) and we are not on the verge of a cure but, rather, are trying to control it in the present.

1-1-1 DEFINITION

Part of the reason we are no closer to finding a cure is the lack of a single, acceptable definition. Historically, the term asthma has been used to denote any sort of difficulty in breathing, especially if there was associated wheeze (Siegal & Rachelefsky, 1985). Wheeze is the term applied to the high pitched whistling sound which accompanies breathing during an attack. It is caused by the forcing of air out through bronchial tubes which are reduced by swelling. Throughout the last 20 years there have been intensified efforts to define asthma, however this has simply resulted in a greater variety of definitions being used by differing researchers. None has gained universal acceptance.

The only similar aspect is that these "definitions" describe the commonly observed phenomenon associated with asthmatic episodes. Most researchers agree that an asthma attack: involves obstruction of pulmonary airways, it is reversible (either by therapy or spontaneously), a variety of stimuli can elicit this phenomenon, the severity can change over time (Hen, 1986; Creer, 1982; Rachelefsky, 1984; Mrazek, 1985; Phelan, Landau & Olinsky, 1982). The problem is that this is not a definition, but rather a collection of symptoms. Differing researchers will place different priorities on each of these symptoms.

Perhaps two of the more accepted definitions are those by the American Thoracic Society 1975 (cited in Mrazek, 1985) and Scadding 1966 (cited in

Phelan, Landau & Olinsky, 1982). The American Thoracic Society state that asthma is a disease characterized by an increased responsiveness of the trachea and bronchi to various stimuli and manifested by difficulty in breathing due to generalized narrowing of the airways. Scadding views asthma as consisting of wide variations (over short periods of time) in resistance to flow in intrapulmonary airways, which is reversible. So it can be seen from these definitions that the condition known as asthma is variable, reversible, intermittent and affects the individual's breathing. One thing that does appear certain however is that the population has a common basic disorder (hyper-reactive airways), the mechanisms of which are obscure. Thus asthma is not a homogeneous, pathologic condition but rather a heterogeneous pulmonary disorder which is characterized by differing criteria (Phelan, Landau & Olinsky, 1982). Until researchers better understand the fundamental nature of asthma, it will probably continue to defy exact definition. This of course has follow-on effects for studies concerned with asthma research and the comparison of findings due to the difficulties in establishing accepted criteria for severity.

1-1-2 TYPES OF ASTHMA

Similarly, there is a problem in establishing a classification system of symptomatology for the broad patterns of asthma and severity of the condition. This has major implications, not only for research but also the diagnosis and level of treatment. There have been many attempts to classify asthma, with Siegal & Rachelefsky (1985) declaring that the one thing that was apparent was that each sufferer should be evaluated and treated as an individual. Despite this, it is still important for physicians to have a firm idea of just how asthmatics differ e.g.) are there different levels of severity and are the clinical manifestations the same?

Perhaps the first major attempt to classify the traditional pathogenesis of asthma was by Rackemann in 1928 (Russo & Varni, 1982). This approach attempted to divide asthma into classes of "extrinsic", "intrinsic" and "mixed" types. Such an approach considers extrinsic asthma sufferers to have a major allergic component within their disease and it's aetiology, whilst the intrinsic sufferer is largely free of atopic symptomatology (Mrazek, 1985). Atopy refers to the development of antibodies in response to antigens. The major problem with this was that many sufferers appeared to fall within the mixed-type.

The next attempt at a classification system was based on the severity of the symptoms, this is widely used today in one form or another. The problems associated with developing such a system are outlined by Creer (1982), with

particular reference to the intermittent nature, severity and reversibility components. The very nature of asthma means that a child may suffer over several days then not be bothered for months. Similarly the severity of attacks is not confined to a uniform pattern. This can vary from a mild attack (tightness in the chest and/or wheezing) through to status asthmaticus, which is a severe airway obstruction causing acute respiratory distress (Phelan, Landau & Olinsky, 1982).

Although there are differing types of attacks brought on by different triggers etc. , there do not appear to be specific sub-entities of asthma (Phelan, Landau & Olinsky, 1982). However from a practical point of view and particularly for assisting in appropriate management, it is useful for physicians to divide affected children into three broad groups. The labels for these three groups tend to vary with researchers and physicians e.g.) mild, moderate, severe (Ellis, 1983), episodic, frequent and chronic severe (Buchanan, 1986), and infrequent episodic, frequent episodic and persistent-chronic asthma (Phelan, Landau & Olinsky, 1982). All of these classificatory systems have a common basis which hinges on the level of medical needs of the sufferer, the frequency of wheezing, doctor and hospital visits as well as the severity of obstruction during attacks.

The classificatory system used within this study will be that set out by Phelan, Landau & Olinsky (1982). Infrequent episodic is used to describe the mildest form of asthma which children suffer, it is of no major concern or disruption to the child's lifestyle. The next classification is termed frequent episodic, which is described as consisting of episodes of wheezing which occur at least every 1-2 weeks with the child being free between bouts. The final (and smallest percentage) are the persistent-chronic asthmatics, these children have a persistent airway obstruction which tends to last for weeks at a time. Each grouping has a management plan and a treatment regime suited to the requirements of the severity. It should be emphasized that these categories are broad distinctions for the benefit of physicians and treatment regimens, the sub-divisions are not precise and there will often be some overlap and commonality between them. The system of Phelan, Landau & Olinsky (1982) is used within the Christchurch Hospital's Paediatric Department.

1-1-3 PREVALENCE

There has been great difficulty in establishing accurate and accepted figures of asthma prevalence. This is due to the uncertainty concerning the definition and it's classification as well as the variations in the interpretation of age of onset and differing methodologies employed. Another possible reason is the

similarity of other clinical disorders which may be a source of confusion. Such disorders include young children's bronchiolitis, whose signs and symptoms can be virtually indistinguishable from asthma.

Prevalence rates throughout the world are generated in a variety of ways such as cases identified by general practitioners, by hospital doctors and populations used in research studies. As has been noted earlier, there is no universally accepted definition therefore it is quite possible that each of these sources may have used different definitions and diagnostic criteria to establish the prevalence rates. Thus the true prevalence rate of asthma in children has not been reliably determined (Siegal & Rachelefsky, 1985).

One finding that should be noted is that the prevalence rate in racially homogeneous populations differ substantially from outbred populations. Ellis (1983) states that asthma is rare among natives on the African Continent, Papua New Guinea and Eskimos. However, with increased urbanization and inter-racial mixing there has been a substantial increase in the rate (Ellis, 1983; Siegal & Rachelefsky, 1985). Reported rates for differing countries vary quite drastically, thus it is difficult to know how validly they can be compared. The rates for children with asthma range from: Finland - 0.06%, Sweden - 1.4%, U.S. - 8.9% and Australia - 11.4% (Siegal & Rachelefsky, 1985).

It can be seen that comparing prevalence rates, which may have been obtained at different times, using different criteria and research designs is fraught with problems. Despite these problems one thing which appears clear from prevalence studies in Scandinavia, Britain, U.S., New Zealand and Australia is that the prevalence of asthma in children has increased since the 1950's (Woolcock, 1986). However, what is not clear is whether this is a true increase or an artifact of better recognition of the disease.

Despite the large variations which exist in the data, it appears that New Zealand has the dubious distinction of having the highest current prevalence rates (Woolcock, 1986). It is estimated that that up to 20% of New Zealanders will suffer from some form of asthma, at some stage of their childhood (Buchanan, 1986). As noted earlier (Phelan, Landau & Olinsky, 1982), this may range from experiencing infrequent episodic attacks through frequent episodic attacks to the most severe form, persistent chronic asthma. The equivalent figures for the U.S. range from 5-10% (Siegal & Rachelefsky, 1985; Ellis, 1983) to 5-15% (Cluss, 1986; Russo & Varni, 1982). Within New Zealand, Buchanan (1986) suggests that 3/4 of all children with asthma suffer the episodic kind, whilst around 25% will have frequent episodes. The smallest number (around 1-3%) will suffer from chronic severe asthma. Figures for the prevalence in New Zealand are just as varied as for overseas, suffering from the same problems of definition etc. Following a review of the New Zealand literature,

Mitchell (1983) states that the estimates of prevalence vary between 1.9%, 5%, 7.1%, 7.9% and 12.2%. In an effort to overcome these problems, Mitchell (1983) replicated a study which was carried out by Milne in 1969. The original study of two North Island intermediate schools used the questionnaire method to establish the prevalence of asthma, the result was a prevalence of 7.1%. Mitchell used the same method and definition as the earlier 1969 study, even using the same two schools for the subject population. Mitchell (1983) found a prevalence rate of 13.5% for the intermediate children; a significant increase on the 1969 findings of 7.1%. The reasons for this increase are undetermined, with Mitchell (1983) speculating either a real increase or better recognition of the condition by contemporary general practitioners.

Along with these findings Mitchell (1983) found a significantly higher rate of asthma among boys than girls, with a ratio of 3 : 2. This concurs with the findings of Sears, Rea, Fenwick, Beaglehole, Gillies, Holst, O'Donnell, Rothwell & Sutherland (1986). As with other prevalence figures the ratio of boys to girls varies with the researcher, ranging from estimates of 1.3 : 1 to 3.3 : 1 (Ellis, 1983). It appears that boys also suffer more severe asthma than girls during childhood (Buchanan, 1986). In fact, Horwood, Fergusson & Shannon (1985) found the "most notable aspect" of their six year prospective study of Christchurch children to be the way the child's sex was associated not only the severity of the asthma but also the factors associated with the condition. No satisfactory explanation has been provided to account for this sex difference, however the discrepancy seems to disappear during adolescence (Horwood, Fergusson & Shannon, 1985 ; Hen, 1986 ; Ellis, 1983 ; Buchanan, 1986).

Regardless of what the actual prevalence is, it is plain that asthma is one of the most common causes of ill health in children. It is of significant concern worldwide but even more so for New Zealanders. Not only did we lead the world in prevalence rates during the 1960's and 1970's but we continue to do so in the 1980's (Woolcock, 1986).

1-1-4 MORBIDITY

This term refers to the negative consequences of experiencing asthma such as hospitalization, visits to the physician and school absences. The prevalence figures for New Zealand portray the extent of the asthma, however they do not show the effect that asthma can have on the lives of child sufferers and their families. Asthma is the most common chronic lung disease in childhood (Siegal & Rachelefsky, 1985) and probably accounts for the most hospital admissions in childhood. A major effect of these attacks is school absenteeism,

it accounts for 25% of school days lost through chronic illness in the U.S. (Hen, 1983, Siegal & Rachelefsky, 1985).

Twelve percent of U.S. children with asthma lose over 30 days schooling per year and those with over 6 weeks absence scored appreciably worse on teachers' assessments of social, psychological and educational adjustment (Anderson et al., 1983, cited in Siegal & Rachelefsky, 1985). The pattern of school days lost appears to be of major significance. Russo & Varni (1982) suggest that frequent brief absences, typical of asthma, are more harmful to academic progress than are occasional longer ones. Such absences typically result in the child falling behind academically, restriction of social/physical activities and a sense of ostracism from the social mainstream.

The extent of hospitalization and its attendant problems is shown by Hen (1986) who states that in the U.S. during 1982, asthma resulted in 388,000 hospital admissions of children under 15 years (average stay = 3.9 days). The admission rates in New Zealand for children under 15 years have increased from approximately 45/100,000 (1964) to 634/100,000 population in 1983 (Mitchell, Ferguson, and Norwood, 1986), whilst the admission rate for the age group 15-44 has increased fourfold (Jackson & Mitchell, 1983). Concurrent with this, Jackson & Mitchell (1983) report a dramatic increase in sales of anti-asthma medications, particularly between 1976-1981. Examples of this are sales of Sodium Cromoglycate which increased 163% for this period and sympathomimetic aerosol sales rose by 225%. However, as these medications may also be prescribed for bronchitis and emphysema not all the increased sales can be attributed to asthma.

Some of these admission rates may be explained by changes in hospital admission criteria and multiple admissions per child. However, the fact remains that there is still a substantial increase in the hospital admissions for childhood asthma. Thus, it can be seen that morbidity is the area where the impact of asthma is most obvious. In addition to the hospital admissions and school days lost, there is the role that asthma plays in restricting the child's activities and, particularly, in generating monetary costs (Russo & Varni, 1982). Such costs include continuing and unexpected physicians' bills plus charges for long-term medication usage. Hen (1986) considers that education of both physicians and parents regarding patient self-management and appropriate care can help to reduce these morbidity rates and associated costs.

1-1-5 MORTALITY

This term refers to a death where asthma causes or is a leading contributor to the death of an individual. When comparing mortality rates between

countries it is necessary to be aware of several possible sources of error. Account should be taken of the reliability of death certification and coding practices, as well as the prevalence rates, variations in severity and treatment of asthma.

The majority of deaths are among the adult population but, increasingly, a significant number of children are losing their lives to asthma. Despite asthma being around for centuries, it has only relatively recently been appreciated that asthma could cause death in children. As late as 1944, only 5 asthma deaths were reported in infants and two in older children. During the 1960's there was an increased number of deaths in the 5-34 years group in England, Wales, Ireland, Australia and New Zealand (Siegal & Rachelefsky, 1985). This rise in mortality has been seen as an international epidemic, beginning in the mid-1960's, for which no satisfactory explanation has ever been found. The important aspect to this epidemic, from New Zealand's point of view, was that all the other countries involved experienced a decline in deaths after 1966. However, New Zealand failed to return to the baseline levels of the pre-epidemic period. New Zealand quickly rose to a mortality rate three times that of the pre-epidemic days, then gradually declined over the next eight years. Unfortunately the rate of asthma related deaths remained at a level 1.5 times the pre-epidemic rate until the mid-1970's.

Following on from this, New Zealand experienced a second epidemic beginning in 1976 which persisted into the 1980's; again, the cause of this epidemic is unknown. The death rate in 1982 was 4 times that of prior the pre-1960's epidemic (Jackson, Beaglehole, Rea & Sutherland, 1982). A review of the mortality literature shows a pronounced increase in New Zealand, from the mid-1970's, which is not apparent in five other populations studied: England, Wales, Australia, U.S. and Canada (Jackson et al., 1982). Such a rise cannot be accounted for by a change in the classification of asthma deaths, inaccuracies of the death certificates or any other distinct variable (Jackson et al., 1982).

New Zealand's high mortality rate, as defined by death certification, has aroused great interest among researchers worldwide. The figures for 1980 show that in the 5-34 years group, New Zealand is well ahead of other western countries with 3 deaths per 100,000. Comparable figures per 100,000 are: Canada - 0.3, U.S. - 0.2, England - 0.2, West Germany - 0.4, Australia - 1.0 (Woolcock, 1986). Even allowing for false positives on death certificates, the New Zealand rate for adults is 3 times that of the U.K. (Sears, Rea, Beaglehole, Gillies, Holst, O'Donnell, Rothwell & Sutherland, 1985). Further, this rate is still much higher even when allowing for the over-representation of Maori and Polynesian deaths due to asthma in the New Zealand figures. This high national rate of asthma deaths is confirmed by Sears et al. (1985); in a two year

study of all asthma deaths for New Zealanders less than 70 years old, they report a rate of 5.1/100,000. Data from this same study were later reported for all asthma deaths for children aged 0-14 years (Sears et al., 1986). The findings show that 16 children died during the two year period, all outside of hospital. Further to this, it showed the mortality rate for Maoris to be 5 times that of Pakehas. But perhaps the most disturbing facet of the study was that Sears et al. (1986) consider, with hindsight, that in eleven of sixteen cases there were factors involved, which if avoided, would have prevented the deaths ! These factors included inadequate treatment due to the attitudes of the family (anti-medication) or the medical advisers and failure to call the physician in time.

There are no data to show a relationship between mortality and patient / parent education concerning asthma. However, retrospective studies show that the sufferer, his/her family and occasionally the physician did not appreciate the severity of the disease (Woolcock, 1986 ; Sears et al., 1986). Amongst all the asthma deaths in people less than 70 years of age, a team of reviewing physicians agreed that, with hindsight and information regarding the patient's care, death was potentially avoidable in 61% of the cases (Sears et al., 1985). Despite this, it must be stated that New Zealand's rate of unavoidable death from asthma is still considerably greater than the U.K. (Sears et al., 1986). This does not appear to be due to problems such as certification of death practices and suggests it may be due to other factors e.g.) a change in the severity of New Zealand's asthma (Sears et al., 1986).

What is disturbing about these asthma deaths, is the lack of any crisis plan within the family and low level of understanding about asthma displayed by those who died. For example, in ten out of sixteen deaths the child had never used a Peak Flow meter to monitor his/her pulmonary function. Further, in only five out of sixteen cases was there any evidence of a crisis plan within the family (Sears et al., 1986). It appears that lack of asthma education is a contributing factor to the mortality rate of New Zealand children. This is reinforced by the above finding of Sears et al (1986) concerning the avoidable nature of death such as maladaptive parental attitudes and not knowing when to call the physician. Woolcock (1986) suggests that families need education concerning medications and management plans in order to reduce this high mortality rate.

1-1-6 AETIOLOGY

The essential factor to understand is that asthma only occurs in those individuals who are predisposed physiologically to the condition, one does not "catch" asthma (Buchanan, 1986 ; Cluss, 1986). There appears to be a basic

defect with all asthmatics which is a predisposition to bronchial hyper-reactivity i.e.. overly sensitive airways. Apart from this common factor each individual will have their own specific stimuli which they are sensitive to and which will "trigger" an attack. Thus, it is against this background of hyper-reactivity that specific stimuli may precipitate an attack.

While no single theory explains completely this predisposition to asthma, there is mounting evidence of a genetic component (Horwood, Fergusson & Shannon, 1985 ; Buchanan, 1986 ; Cluss, 1986 ; Ellis, 1983 ; Hen, 1986 ; Burrows, 1987 ; Siegal & Rachelefsky, 1985). It appears to be the fundamental abnormality of the hyper-reactive airways which is transferred genetically. An in-depth physiological analysis of the causes of asthma and their effects is beyond the scope of this thesis (see Phelan, Landau & Olinsky, 1982). This paper shall address the major genetic transmission concept, then briefly describe the major triggers of asthma attacks.

Genetics

Siegal & Rachelefsky (1985) state there is a large amount of evidence that genetics play a major role in the pathogenesis of asthma. However, the specific mode of this genetic transmission has not been completely resolved (Hen, 1986 ; Siegal & Rachelefsky, 1985). It was initially thought that inheritance of asthma always involved the expression of atopy (defined as the developing of antibodies, primarily IgE immunoglobulin, in response to various antigens). However it is now clear that asthma can be inherited independent of atopy (Siegal & Rachelefsky, 1985 ; Cluss, 1986). Siegal & Rachelefsky (1985) speculate that although atopy itself does not predispose an individual to asthma, it may enhance a genetic susceptibility to the condition, therefore increasing the likelihood it will be expressed. By tracing the family history of a given asthmatic, it is commonly found that there is a significant increase in asthma, hayfever and eczema in parents, siblings and grandparents when compared to control groups (Burrows, 1987; Phelan, Landau & Olinsky, 1982). Further proof of the genetic transmission theory is gained from studies of twins, where there is strong evidence to show that both the propensity to manufacture IgE antibodies and to develop asthma are under genetic control (Siegal & Rachelefsky, 1985). Phelan, Landau & Olinsky (1982) state that monozygotic twins have a 19% concordance for asthma as against a 5% concordance for dizygotic. However, the evidence for a linkage between these genetic controls and the development of hyper-reactive airways is inconclusive. Although the concordance rate for the expression of asthma is significantly higher in monozygotic twins, it must be stressed that this concordance is incomplete (Ellis, 1983 ; Siegal & Rachelefsky, 1985). Phelan, Landau & Olinsky (1982) state

that with identical twins there can still be considerable variability in the patterns of asthma expressed i.e. only one twin may have asthma or else asthma of a less serious nature. Thus it appears that there are important environmental factors which also play a role in expressing the condition.

Triggers

Infections: This specifically refers to respiratory viral infections and not bacterial infections. Infections are one of the commonest causes of asthma attacks (Buchanan, 1986) yet how or why they provoke the attacks is not completely understood (Buchanan, 1986 ; Hen, 1986 ; Siegal & Rachelefsky, 1985). It is proposed that the viral infection may be one of the factors capable of converting the genetic predisposition of the child into asthma (Siegal & Rachelefsky, 1985).

Allergens: This type of attack is precipitated by an immediate hypersensitive reaction to individual-specific allergens, which are usually inhaled (Rachelefsky, 1984). Such allergens typically include grass, pollen, pets and house dust-mites. However it is by no means certain that all asthmatic children will have an allergy which triggers an asthmatic attack. As has been stated earlier, it is possible to inherit atopy and the asthmatic predisposition separately. It appears that the immune system is implicated by over production of IgE, in response to allergens which are inhaled from the environment (Cluss, 1986 ; Rachelefsky, 1984). If the child is not removed from these allergens, then there is an interaction between the allergen and the antibodies which results in the release of chemical mediators, leading to an asthma attack (Phelan, Landau & Olinsky, 1982). The principal mediator released is Histamine. This is actively secreted by the cell after the interaction of the allergen and the surface IgE. Histamine leads to the breakdown of the tight interepithelial cell junctions and allows further ingress of allergens and further mediator release. Chemical mediators are thought to cause airway narrowing by mucosal oedema, stimulating mucus secretion and smooth muscle spasm (Phelan, Landau & Olinsky, 1982).

Exercise: This will induce asthma attacks of varying degrees of severity in 90-95% of all sufferers (Rachelefsky, 1984 ; Siegal & Rachelefsky, 1985). It manifests itself in increased hyper-reactivity of the airways, resulting in increased secretion of mucus, narrowing of the airways and the expected difficulty in breathing. However, the degree of exercise induced asthma (E.I.A.) does not correlate with the severity of an individual's asthma. E.I.A. may resolve itself 20 minutes after exercise has ceased or respond to a bronchodilator; it may also persist for years after asthma has ceased to be a clinical problem (Siegal & Rachelefsky, 1985). However, it should be noted that

despite the incidence of E.I.A., there is no reason why children with asthma cannot participate in all or most types of physical activity - providing that adequate pharmacological management is available.

Psychological Factors: Psychological factors are not implicated in the aetiology of asthma (Cluss, 1986); the individual must have a physiological predisposition to manifest the condition. However, it has been established that they are important for some patients in the precipitation of attacks (Cluss, 1986; McNichol, Williams, Allen & McAndrew, 1973; Schwartz & Johnson, 1985 ; Davison & Neale, 1982 ; Bellack, Herson & Kazdin, 1985). The relative contribution of these factors will vary from person to person as well as within individuals across time. Thus, one episode of asthma may be precipitated by psychological factors whilst the next may be due to purely physiological triggers or a combination of both (Schwartz & Johnson, 1985). Rees, 1964 (cited in Schwartz & Johnson, 1985) found in their study that 21% of subjects experienced attacks which were due to psychological factors alone. The implicated factors are:

- a) *stress*, either as a precipitator or exacerbator (McNichol et al., 1973; Bellack, Herson & Kazdin, 1985 ; Davison & Neale, 1982)
- b) *emotional behaviours*, such as crying, anger, depression, anxiety and anticipated pleasurable excitement (McNichol et al., 1973; Creer 1982; Davison & Neale, 1982).
- c) *familial variables* such as conflict, this may be either inter - sibling or parent - child (Schwartz & Johnson, 1985 ; Davison & Neale, 1982).

Any psychological problems a child may have are generally secondary to the asthma, however psychological factors may trigger attacks and/or worsen any existing attack.

Environmental Factors: Each individual will react differently to a variety of stimuli in the environment. However, a major factor involved in inducing asthma is the concentration of pollutants and allergens due to climatic and environmental changes (Siegal & Rachelefsky, 1985). Other common triggers in the environment are pollens , paint and aerosol fumes and particularly cigarette smoke; either actively or passively inhaled. The basic response to encountering these stimuli is an aggravation of the already hyper-responsive airways, leading to an exacerbation of symptoms or an attack of varying severity.

1-1-7 DIAGNOSIS AND ASSESSMENT

A major problem with diagnosing asthma is that there is no generally accepted definition, a fact which is compounded by asthma being of individually variable severity. Rather, asthma is a condition associated with a complete spectrum of symptomatology and degrees of severity. As has been noted earlier, individual children may suffer only infrequent minor attacks whilst others are affected by severe chronic airways obstruction. Asthma is difficult to diagnose in young children, because symptomatology such as wheezing and atopy are common and can be symptomatic of other disorders e.g.. bronchitis (Siegal & Rachelefsky, 1985 ; Vermeire, Wittesaele, Janssens & DeBacker, 1986). This difficulty in diagnosing is a problem by itself as most symptoms are likely to begin during the first year of life (Burrows, 1987) and up to 50% of asthmatic children experience some symptoms by 2 years of age (Siegal & Rachelefsky, 1985). This is very important because improvement in accuracy of diagnosis and care of asthma by general practitioners has been found to lead to reduced levels of morbidity and mortality (Barrit & Davies, 1986).

In many children with asthma, particularly those with infrequent episodes, a diagnosis can be made on the patient's history alone and sufficient treatment instituted. However in some, especially in the more severe cases, it is essential to establish a diagnosis and then monitor the response to therapy (Phelan, Landau & Olinsky, 1982). The primary purpose of a diagnosis is to establish the existence of the condition and determine the source of the airway obstruction which is producing the symptoms. Further to this, is the need to establish the factors linking environmental and physiological variables to the attacks. The general steps used by a physician to establish a diagnosis of asthma, determine the severity of the condition and therefore it's therapeutic regimen are set out below. As previously mentioned, the exact symptoms necessary for a diagnosis of asthma may well vary between physicians, especially so as regards assessing the severity. To cover all symptoms and their relationship to differing degrees of severity falls within the purview of a medical text rather than this paper. Table 1 describes a list of asthma symptomatology and requisites for assessing severity as set out by Phelan, Landau & Olinsky (1982).

Table 1: Asthma symptomatology for assessment of severity

<u>Severity Classification</u>	<u>Symptoms</u>
Infrequent Episodic	viral upper respiratory infection; e.g.. rhinorrhoea, mild fever, sore throat after 1-2 days : cough and wheeze symptoms worse at night
Frequent Episodic	wheeze, difficulty in breathing. Early episodes are associated with symptoms of acute respiratory infection. Occurrence is associated with weather changes, exposure to allergens, physical activity and emotional stress. Symptoms are worse at night especially coughing.
Persistent or Chronic	Half of these children experience prolonged wheeze in the first two years of life. By 5-6 years, children will be wheezing most days with nights disturbed by cough and wheeze. Occasional acute exacerbations of airways obstruction. Possible abnormal signs in the chest, breathlessness.

Establishing a diagnosis:

History: During the initial consultation, attention should be directed toward the nature and pattern of symptoms, particularly the triggers. In addition, the development of asthma family history and the child's general medical history will offer valuable information (Siegal & Rachelefsky, 1985 ; Buchanan, 1986).

Physical examination: This should include the detection of signs of symptoms such as; wheeze, cough and chest pain. Also important to consider is the presence of allergic reactions e.g.) eczema and hayfever etc. However it is important to note that there may well be no evidence of all or any of these, there may just be a cough (Phelan, Landau & Olinsky, 1982 ; Siegal & Rachelefsky, 1985).

Clinical examination: This may include a variety of tests to help confirm or deny the diagnosis of asthma. The most basic would be a measure of pulmonary function which would compare an individual's rate of expiration to established norms. This is an objective measure of the degree of airway obstruction and it's reversibility. Measurement is obtained by having the child

blow into a peak-flow meter (Wright, 1978), which records the amount of air expired from the lungs in the first 0.1 seconds. These measures can also be used to give an index of change in the condition over time (Russo & Varni, 1982), which is necessary as asthma is such an unpredictable condition.

Another method for use in the clinical examination is exercise provocation to see if there is any change in lung function pre and post exercise. Objective assessment of any change will be obtained via readings on the peak-flow meter; readings will be compared on a pre-exercise and post-exercise basis. If asthma is present, the post-exercise reading will be lower due to the characteristic narrowing of airways. The idea of skin tests has lost favour as a routine test due to the fact that some children have multiple allergies, also it is possible to have allergies without their being triggers of asthma.

1-1-8 PROGNOSIS

The prognosis for all asthma sufferers is not completely certain. Asthma can usually be controlled by current pharmacological treatment, however it is difficult to forecast the course of an individual's disorder (Creer, 1982). Estimates for "growing out" of asthma vary according to the study one reads, they range from 26%-78% of asthmatics (Creer, 1982; Russo & Varni, 1982), with several studies stating that a significant number of children will outgrow asthma as they age (Siegal & Rachelefsky, 1985; Burrows, 1987; Ellis, 1983), although the age that this occurs ranges from mid-childhood to adolescence.

Perhaps the best source of information regarding prognosis comes from the Melbourne community based epidemiological study of 1969 which is reported in Phelan, Landau & Olinsky (1982). This prospective study followed a group of asthmatics through their development and at age 21 saw 80% of subjects. It was found that age of onset of asthma had no prognostic significance whilst the two factors with greatest prognostic value were the presence of eczema and frequent episodes of prolonged wheezing before age two. Such subjects had continual frequent or persistent asthma at age 21. It also appears that most children with persistent asthma at ages 10 and 14 continued to have quite frequent or persistent asthma into early adult life (Phelan, Landau & Olinsky, 1982; Hen, 1986;).

1-1-9 TREATMENT

The aim of asthma therapy is to allow the child to participate fully in his/her ordinary activities with a good degree of bronchodilation and reduced airway reactivity. The primary method of treatment is pharmacological. The particular type of drugs prescribed would depend on the severity of the

individual's asthma. Pharmacological agents fall into three broad groups : a) Those which relieve symptomatology of asthma b) those which act prophylactically i.e. prevent bronchial muscle spasm and swelling of linings of mucous membranes c) steroid medications which are used for severe cases. Steroids may act as either a reliever or prophylactic depending on the dose and regimen prescribed. Table 2 is an outline of common asthma medications used in New Zealand at the present time. They are listed by their classification. Particular brands may vary with physicians and hospitals; those presented are currently prescribed at Christchurch Hospital's Paediatric Department. For a detailed account of asthma medications, their typical dosages and specific effects refer to Appendix 1.

Table 2 : Common asthma medications within New Zealand

Relievers -	Berotec, Bricanyl, Ventolin Theophylline medications such as Nuelin, Nuelin-SR, Theodur
Preventers -	Intal, Vicrom Inhaled steroids such as Aldecin, Becloforte, Becotide
Steroids -	Prednisone in tablet form Hydrocortisone in injection form

The second phase of treatment is to discover particular irritants and/or allergens which irritate the individual's airways. The aim is to encourage the child and family to either avoid, or if possible eliminate, the offending substances. If the allergens cannot be avoided or eliminated and pharmacological agents are of little help then an allergy desensitization programme maybe considered to allow functioning in the precipitating situations.

There have been great advances over the years in the type of asthma medication which is available and its mode of delivery e.g.. improved inhaler technology and longer lasting medications. It is now quite possible to control most individuals' asthma to an acceptable limit. However, the best medicines in the world are of no effect if the prescribed regimen is not adhered to, thus the issue of compliance with medical regimens is of prime importance (Cluss, 1986 ; Rachelefsky, 1984).

1-1-10 ROLE OF PSYCHOLOGY IN CHILDHOOD ASTHMA

Psychosomatic medicine, where symptoms are physical but psychological factors may serve to maintain or worsen symptoms, is an area where the psychologist has much to offer. Asthma is a classic example, where attacks may be precipitated by psychosocial stimuli which serve to influence the frequency, severity and/or duration of symptoms (Schwartz & Johnson, 1985).

For the psychologist, the aim is to be aware of and address the interrelationship between psychological and social variables and the health status of the patient. Behavioural techniques have been successfully employed to decrease anxiety, and alter behaviours accompanying attacks as well introduce management skills to the behaviour repertoire. The expertise of the pediatric / behavioural psychologist is in blending the medical needs with the behavioural approach to prevent/alter problems associated with childhood asthma. Total management of asthma must include both these medical and behavioural approaches in the goal of making the individual self reliant. Three areas in which the psychologist can help are:

- a) dealing with problems associated in complying with medical regimens
- b) educating the patient plus his/her parents to the necessities and realities of life with asthma.
- c) providing strategies to deal with stressors which may be implicated in precipitating or exacerbating attacks.

1-2 COMPLIANCE WITH MEDICAL REGIMENS

According to Blackwell (1979) the issue of medical compliance with prescribed medications only become an issue during the 1970's. This was due to an awareness that no matter how powerful the medication, it was of no use if administered incorrectly. Factors which promoted this interest were a decrease in the rate of new medication discoveries and new technology which permitted detection of a medication's presence within the body (Blackwell, 1979). Allied to this were escalating costs associated with healthcare and the dangers of misusing potentially toxic medications (Baum & Creer, 1986). Today it is accepted as one of the most important, yet poorly appreciated problems facing medical management (Spector, 1985).

As acute and infectious diseases became more preventable and easier to treat, the focus of clinical research and practice has shifted towards the prevention and management of chronic disorders (Russo & Varni, 1982). With this shift towards disorders where chronic symptom management instead of cure represents the primary focus of treatment, children and their families become increasingly more instrumental in the health care system. Simply prescribing medical regimens is not a sufficient condition to assure implementation of regimens; behavioural and psychosocial factors may prevent or impede the therapeutic process (Russo & Varni, 1982).

An area of special concern is the paediatric population, (Radius, Becker, Rosenstock, Drachman, Schuberth & Teets, 1978) where compliance is often less than optimal. This may be readily seen in the chronic diseases of childhood; of which asthma is a prime example. The mainstay of modern asthma management is pharmacological therapy, often associated with complicated regimens for administration. However, as Voyles & Menendez (1983) point out this chronic pharmacological therapy can only be effective if the parent and child are conscientious about consistent medication usage.

1-2-1 DEFINITION

Although researchers readily agree that non-compliance is a problem in healthcare, what they cannot agree upon is an accepted definition of the term non-compliance. Masek & Jankel (1982) suggest that the definitions are as varied as the diagnosis, measurement systems and types of therapeutic regimens investigated. At a global level the term can be defined as some failure to achieve a treatment goal (Masek & Jankel, 1982), which although it is directional is not specific enough. To add confusion, the range of behaviours which non-compliance can be related to is broad as well: failing to keep an

appointment, insisting on discharging oneself from the hospital against medical advice (Meichenbaum & Turk, 1987), a failure to take preventive steps to reduce the risk of illness reoccurrence (Matus, 1981) or the commonly cited failure to take medications as directed (Baum & Creer, 1986; Meichenbaum & Turk, 1987; Matus, 1981; Kellaway & Brown, 1983).

The dilemma of formulating an exact definition of just what non-compliance refers to is illustrated by the above examples; indeed it is true that they are all possible areas where the term compliance can rightfully be used. Shope (1981) raises another problem with any single definition which is related to the fact that compliance or non-compliance can occur in varying degrees. Studies to date have employed different criteria when establishing rates of compliance for subject populations and Shope (1981) suggests that it is necessary to be aware of this fact when looking at any compliance research. It is possible that non-compliance can be seen as when an individual never complies with recommendations, only sometimes complies or does not always comply as instructed. Thus, it is feasible that different researchers may employ different criteria according to their own needs.

Kellaway & Brown (1983) further complicate the issue by suggesting that non-compliance can be deliberate by the patient, unintentional due to errors or even adaptive in the case of poor prescribing. Thus it requires that any single definition must take account of the motivation involved with the non-compliance. Even the use of the very term compliance has been questioned by some researchers (Meichenbaum & Turk, 1987; Shope, 1981) who feel it has negative connotations. It is their contention that "compliance" implies that the patient must follow orders and is deviant if he/she does not. This suggests that no awareness is taken of the fact that the non-compliance may well be completely unintentional (e.g.) due to misunderstandings.

It is apparent that there are many issues associated with the definition of compliance, and hence non-compliance, thus preventing a single definition. In light of this, it seems that researchers will continue to employ the definitions and relevant criteria which are most appropriate for their particular study. Due to this, Shope's (1981) warning concerning the need to account for the definition when reviewing data will continue to be germane. The present study, which is researching compliance with medical regimens in an asthmatic population, will employ the definition offered by Baum & Creer (1986). This definition states that compliance is the extent to which a patient's behaviour complies with a clinical prescription and incorporates the accepted notion of failing to take medication as directed (Meichenbaum & Turk, 1987; Matus, 1981; Kellaway & Brown, 1983). The criteria for a recording of non-compliance will be any incidence where medication is not administered as directed by the

physician either in terms of quantity or frequency. The compliance issue dealt with will refer to prescribed medications and will not address related prescribed or suggested lifestyle changes.

1-2-2 EFFECTS OF NON-COMPLIANCE

Perhaps the most important and regrettable effect of non-compliance by sufferers of asthma is that they are deprived of their optimal health status (Shope, 1981). The basis of asthma therapy is the continued use of pharmacologic agents and it is only by this continued correct administration that chronic asthma can be managed. If the medication is not used in the correct fashion, then the sufferer lays him / herself open to increased rates of morbidity and in some cases mortality (Deaton, 1985). Cluss & Fireman (1985) report that non-complying asthmatics experience a greater number of days with wheeze, are more likely to experience asthma symptoms in general and demonstrate significantly lower and more variable peak-flow scores than do controls. The least that non-compliant asthmatics can realistically expect is the possibility of higher levels of disruption in their activities and increased interference in their normal daily functioning. Thus, in personal terms it can be seen that non-compliance is potentially hazardous and whatever control of the condition has been experienced in the past is compromised by the irregular administration of medication. Also the prophylactic benefits from asthma medication are only experienced by continued, regular doses of the medication; intermittent administration is subtherapeutic.

The job of the physician is made more difficult if the patient does not comply with his / her prescribed medical regimen; particularly if the patient fails to disclose this information. If a patient presents his / her symptoms as unimproved by medication then a physician will normally change the dosage or else the medication, in an attempt to achieve therapeutic efficacy (Smith, Seale & Shaw, 1984). However, if the failure to improve is due to a lack of non-compliance the physician may unwittingly prescribe a possibly dangerous level of medication, due to an assumption that the lower dose is not working. Further, the physician may be led to interpret the patient's condition as worse than it actually is. This may result in the prescribing of a medical regimen suited to the presenting symptoms yet wholly unsuited to the patient's real condition (Shope, 1981). Further, in an attempt to gain a clearer clinical picture a physician may order unnecessary tests (Shope 1981) which can result in a considerable burden on the health budget. A by-product of this non-complying and unnecessary alteration of medications prescribed is the cost of waste (Kellaway & Brown, 1983; Deaton, 1985). It can be seen that non-compliance with prescribed medical regimens has serious implications for the asthmatic

individual. However, the non-compliance also affects the physician's therapeutic recommendations and ultimately the New Zealand taxpayer.

1-2-3 RATES OF NON-COMPLIANCE WITH ASTHMA

The issue of non-compliance with prescribed medical regimens has come to be an area of great concern for researchers. Prior to 1974 the number of published articles was 245 yet by 1977 this had increased to 853 (Masek & Jankel, 1982). However, as noted earlier (Shope, 1981) the figures concerning rates of non-compliance vary greatly according to the researcher and methods employed.

The level of compliance varies depending on the form of treatment regimen, with the highest rates being associated with direct medications (e.g. injections) and close supervision (e.g. inpatient care). Meichenbaum & Turk (1987) state that the lowest rates are among patients with chronic disorders, especially when no immediate discomfort or risk results from non-compliance. Asthma is a prime example of this. Chronically ill asthmatic children require long-term therapy, however such sufferers do not see immediate results from complying nor experience immediate discomfort through non-compliance with prophylactic medications.

The physician or healthcare provider is probably in the worst position to detect non-compliance yet paradoxically he / she is the one who requires this knowledge most. The main reason for this lack of awareness is the patient's unwillingness to disclose non-compliance. In general, methods of detection for non-compliance are not available to the doctor or else are unreliable. Possibly the most common reason of all however is that physicians fail to enquire routinely about compliance rates (Meichenbaum & Turk, 1987; Marion, Creer & Burns, 1983). The problem of objective rates of non-compliance is not solved completely by formal research methods. Most studies employed populations who volunteer or at least agree to take part which may mean they are unrepresentative of the typical patient population. Such voluntary subjects are in essence self-selected, often more committed and in turn more compliant with requests and therefore medical regimens (Meichenbaum & Turk, 1987). This may then result in a low level of non-compliance which is unrepresentative of the population.

Perhaps the best opportunity to test compliance levels with asthma medications is within the emergency room environment. This involves objective assessment of medications present in a patient's system when he/she presents for emergency treatment. This would presumably be a situation where unwillingness to disclose and demand characteristics are at their lowest.

The most common measure within this area involves the bioassay of serum Theophylline levels within the patient's blood. The amount present is compared to what is considered to be therapeutically viable for that individual based on age and weight. Three studies have reported compliance levels specifically relating to the emergency situation. All studies state that in excess of 70% of those presenting were found to be non-complying i.e.) the patients were found to have insufficient levels of medication to achieve therapeutic effects (Weinstein, 1984; Marion, Creer & Burns, 1983; Wood, Casey, Kolski & McCormick, 1985).

Although these figures show that a large proportion of asthmatics are not complying with their medication regimens in some way, it is interesting to look at other studies concerning the level of compliance. Spector (1985) reports that of a group of children on Theophylline medication only 11% were found to have therapeutic levels of theophylline within their systems. Further, 65% of the subjects were deemed to have less than therapeutic levels whilst 24% actually had no measurable Theophylline within their system. Spector (1985) also reports on another study with asthmatics, except this time all subjects were given directive remarks, by both doctors and nurses, concerning the need to comply. The findings, however, show that despite encouragement only 42% had Theophylline levels within the therapeutic range whilst 6% demonstrated no measurable levels at all. A factor to bear in mind concerning the above figures is that individuals may have differing metabolic rates. This may result in some individuals "using up" the Theophylline faster than other, similar weight patients. If this is so, any bio-assay would show the level of Theophylline as being below the expected therapeutic level. This would then result in the patient being labeled as non-compliant, although the real reason is an increased metabolic rate.

As has been stated earlier, the level varies according to the researchers and their methods employed. The most reliable figures appear to be within the 30-50% range and may be summarized as follows:

36% - (Deaton 1985; Radius et al., 1978; Cluss & Fireman 1985; Becker, Radius, Rosenstock, Drachman, Schuberth & Teets, 1978)

50% - (Weinstein, 1985; Blackwell, 1979; Weinstein, 1984; Rapoff, 1986; Weinstein & Cuskey, 1985).

Figures for New Zealand studies appear to be in line with these estimates. Kellaway & Brown (1983) found 58% of patients, who had not received counselling regarding medication compliance, to be non-compliant. The subjects were previously either inpatients or else referrals from the community. All subjects were interviewed to establish their compliance with medication as prescribed.

1-2-4 MEDICATION COMPLIANCE WITH OTHER POPULATIONS

The problem of achieving compliance with medical regimens is by no means unique to the care of asthma sufferers. The literature from a diverse array of medical conditions, especially chronic, suggests that less than optimal rates of compliance is the norm rather than the exception. It appears that even despite repeated warnings from physicians and detailed explanations of negative outcomes, patients continue to be non-compliant.

Meichenbaum & Turk (1987) report on a group of glaucoma sufferers who were informed of the necessity to use eye-drops three times per day or else blindness would result. Of these patients, 58% were found to be utilizing the eye-drops less than prescribed, even though they knew this non-compliance would have serious ramifications. Spector (1985) also reports findings with a series of sufferers from chronic conditions which all had serious implications for non-compliance with medical regimens. Spector (1985) states that of patients required to take anti-hypertensive medications on a regular basis, only 53% were found to be complying with prescribed rates. In addition, Spector (1985) reports that a study-population of diabetes sufferers were found to take the prescribed amount at the required interval only 48% of the time.

Other conditions where compliance rates are less than optimal are reported by Pelco, Kissel, Parrish & Mittenberger (1987) and include the following: leukaemia, hyperammonemia and Nephrotic Syndrome. However, no specific rates are available from this source.

1-2-5 MEASUREMENTS EMPLOYED TO ASCERTAIN COMPLIANCE RATES

The basis to establishing rates of compliance (as previously defined) within asthmatic populations, or any medical condition, is the monitoring of medications administered. Without this measure of the compliance behaviours under investigation, it becomes impossible to distinguish between treatment failure and non-compliance (Weinstein & Cuskey, 1985). The exact means of establishing compliance will differ between researchers but it is essential to be aware of the approaches used for any figures reported. Currently, there are two distinct approaches employed:

- (a) bio-assay which is the measuring of some substance present in the patient's body which is reflective of the regimen under investigation
- (b) behaviourally based observation methods which generally involve the reporting of medication administrations or direct observations.

Bio-assay is the most objective of the methods employed, it involves the sampling of blood, urine or saliva from a patient and testing for the presence of the medication in question or else a pharmacologically inert substance used as a tracer. Masek & Jankel (1982) suggest that this is the standard by which other assessment methods are compared. The prime advantage is in the objectivity of assessment however it is not without its problems which include issues of practicality and cost. The reliability of such measures has also been questioned with differing levels being reported by separate laboratories for samples obtained from the same patient. Further, bio-assay fails to account adequately for differing metabolic rates between individuals. This method is not suited to all asthma medications e.g. inhaled substances and is mostly used to determine serum Theophylline levels. Theophylline is particularly suited to this form of measurement as it is directly accessible via blood samples and there is an accepted band of therapeutic efficacy which physicians consider necessary to be present (10-20 mcg/ml). However, the objectivity it provides is not conclusive as it does not manage to overcome all sources of bias. One factor which should be mentioned is that the level of compliance established is only a gross measure. The reading obtained is simply for the instance assayed and gives no indication of the pattern of compliance.

The most frequently employed behaviourally based measurement in the asthma compliance literature is the self report of administration (Masek & Jankel, 1982). This involves the subject recording, usually daily, the quantity and frequency of medication administration. This method is equally useful with either liquid, aerosol or pill forms of medication in that the subject need only fill in a chart after administrations. One of the major criticisms regarding accuracy is that filling out the record sheets may well act as a cue to administer the medication, thus altering normal behaviour. Masek & Jankel (1982) state that self-monitoring is a powerful compliance enhancing technique. The other major criticism of the measurement method is the opportunity to record false administrations either due to dishonesty or demand characteristics. However, despite these concerns it appears that subjects are able to predict and record with accuracy their rate of compliance. Radius et al, (1978) compared the self-monitored recordings of medications administered, with objectively obtained (bio-assay) estimates of compliance and found a correlation of 0.91. The authors state that mother's recordings may serve as useful alternatives to the less accessible objective indicators of compliance. These findings have been reinforced by subsequent research. Smith, Seale & Shaw (1984) found maternal records of aerosol usage to be valid by comparing serum Theophylline levels with maternal statements regarding compliance. The researchers found a 90% agreement rate between the maternal statements and the objective measures employed. Such high correlations between maternal

self-reports and actual medication compliance have been reported by other researchers, who all found maternal recordings to be a valid form of measurement (Shope, 1981; Smith, Seale, Lay, Shaw & Bracs, 1986).

In order to further enhance the reliability of behaviourally based measurement methods Masek & Jankel (1982) suggest that self-reporting should be combined with either biochemical or physical objective data. The physical data may be obtained by daily readings of the peak expiratory flow from the sufferer. These readings will indicate whether the pulmonary function is within acceptable limits. If medication has been complied with, then the pulmonary function will be within established norms for a child's age and height (St George, Reid, Grimmond & Morton, 1982). These pulmonary function tests have been employed by several researchers, each reporting satisfactory results (Baum & Creer, 1986; Cluss, Epstein, Galvis, Fireman & Friday, 1984; Spector 1985).

1-2-6 HOW TO IMPROVE COMPLIANCE WITH MEDICAL REGIMENS

Rapoff (1986) states that involvement of parents is vital for any efforts to initiate or maintain compliance with a child's medical regimen to be successful. For this involvement to be successful the parents need an understanding of what is to be done and what is expected of them. Although this understanding is important for maximum compliance, Parrish (1986) suggests that general information concerning a disorder and its management is seldom sufficient by itself. It is seen as central to compliance behaviour that the individual possess the skills and resources necessary to engage in the desired compliance behaviour (Parrish, 1986; Meichenbaum & Turk, 1987).

The most successful of approaches to increasing compliance has been the use of behaviour modification strategies (Meichenbaum & Turk, 1987). Such strategies involve employing training procedures, designed to promote the acquisition of skills required for compliance. The management of asthma related behaviours and associated negative practices such as non-compliance show good response to modification strategies taught to the child and his / her parent (Rakos, Grodek & Mack, 1985). The behaviour modification approach rests on the premise that an individual's behaviour is influenced by the antecedents and consequences of action. Antecedents are external and internal events which trigger a behaviour e.g.) the decision to take medicine. Consequences of a particular behaviour refer to the rewards or punishments received upon exhibition of the behaviour, the nature of the consequences will in part determine whether the behaviour is repeated or deleted from the repertoire (Meichenbaum & Turk, 1987). By employing training methods

designed to utilize these factors, it is assumed behaviours necessary to comply with medical regimens can be modified or included in an individual's repertoire. The aim is to present the specific skills necessary for compliance and ensure their learning, maintenance and possible generalization by way of behaviour modification techniques. Subsumed under the term behaviour modification are a variety of diverse yet often complementary techniques designed to alter behaviour patterns of an individual. Detailed below are the techniques which have proved to be successful in increasing compliance with medical regimens with medical populations.

Communication and Assertiveness Training

An area of great concern regarding medical compliance is the appropriate use of inhalers (Paterson & Tarala, 1981) and the administration of oral medications (Rachelefsky, Wo, Adelson, Mickey, Spector, Katz, Siegal & Rohr, 1986). A direct method of learning the relevant skills needed here would be to seek advice from the general practitioner, however, Marion, Creer & Burns (1983) state that parents do not receive all the information necessary. Thus it is suggested that the physician must also bear some responsibility for enhancing communication. Areas of concern include the excessive use of technical language and apparent unwillingness to listen to the patient. Further, Rapoff (1986) suggests that parents often do not ask relevant questions concerning medications and the prescribed regimens. The reasons for this are varied but tend to include the fear of appearing "simple", a lack of confidence and being intimidated by the environment/situation. Meichenbaum & Turk (1987) state that the relationship between parent and physician is critical in affecting the compliance process. Weinstein (1985) concurs by stating there is significant evidence that the nature of the communication process and relationship between physician and patient are strong predictors of compliance.

The cornerstone to this improved relationship is better communication and this requires the teaching of appropriate skills to both parties, as well as assertiveness training for the parents (Blackwell, 1979; Smith et al, 1986; Rapoff, 1986). When the parent feels he / she is an active partner with the physician and is able to understand what the physician requires compliance is enhanced. (Bruhn 1983). In order for better communication to ensue it is necessary to provide parents with methods / skills which enable them to better present their situation and clarify these requirements to the doctor. This involves parents requesting plain language, explanations and the writing down of questions they want answered or information they receive. Thus parents need to be able to request information of doctors in a way which is conducive to a positive relationship.

Self-Monitoring of Behaviours

The central feature of changing behaviours is the need to increase self-awareness of the behaviour's exhibition (Meichenbaum & Turk, 1987). Awareness, through the use of skills such as recording, interpreting and responding to the results needs to be explicitly taught to individuals allowing for an understanding of what needs to be done. In some cases self-monitoring alone can lead to increased compliance (reactivity effect) but it is usually used in conjunction with other skills (Meichenbaum & Turk, 1987).

Self-monitoring involves the recording of behaviours exhibited by an individual (on readily accessible recording sheets). These recording sheets range in format from single page sheets where the individual ticks the appropriate boxes to detailed forms where the individuals rate / record feelings and thoughts as well as behaviours. In addition to promoting awareness of the level of a particular behaviours, self-monitoring may act as a form of immediate reinforcement for having completed a particular behaviour once it is recorded. The feedback obtained through monitoring behaviour results in increased parental compliance regarding administration of their children's medication (Parrish, 1986). Such an approach has been used extensively and with success with families of juvenile diabetes sufferers (Varni & Babani, 1986). The self-monitoring involved recording of testing behaviours and results of blood and urine tests; the level of glucose is important for establishing the amount of insulin to inject. Epstein, Beck, Figueroa, Farkas, Kazdin, Daneman & Becker, 1981 (cited in Varni & Babani, 1986) employed self-monitoring with a diabetic population and obtained a significant decrease in the number of positive urine glucose tests.

Self-monitoring skills have an established part to play in increasing compliance among parents of asthmatic children (Lines, 1986; Weinstein & Cuskey, 1985). This involves the daily recording of a variety of behaviours considered necessary to good compliance. Such behaviours include the recording of medications administered, peak-flow readings and asthma related symptoms. An extension of self-monitoring is the keeping of an asthma diary which may act as an evaluator of compliance behaviours (Parrish, 1986) and also allow parents to see, over time, how consistent compliance can lead to improvements in symptomatology (Rapoff, 1986). Benefits of asthma diaries include the detailing of accurate information and compliance behaviours which can prove invaluable to the physician during consultations and also lead to improved compliance with medical regimens (Lines, 1986).

Reinforcement Procedures

Perhaps one of the most used compliance enhancing techniques, use of reinforcement procedures, has been used with a wide variety of conditions including diabetes, asthma, people suffering from hypertension and patients within renal units (Meichenbaum & Turk, 1987). Such contingency management procedures have involved the use of positive reinforcement, response cost and self-reinforcement within all the above populations (Meichenbaum & Turk, 1987). The technique which has met with the best success is the use of a points system within a given population. This involves the earning of a predetermined number of points every time a particular behaviour is exhibited, points are exchangeable for desired rewards. This procedure has led to the increase of compliance rates with sufferers of diabetes (Meichenbaum & Turk, 1987; Melamed & Siegal, 1980) and also patients with haemophilia regarding exhibition of prescribed exercises (Varni & Babani, 1986). The use of contingency management procedures must surely have applications within the paediatric asthma population.

Reminder Behaviours

One of the problems associated with any chronic medical regimen is that people simply forget to do what has been prescribed, either completely or at the wrong time (Rapoff, 1986). The use of cues and reminders can encourage compliance behaviours and increase the rate of exhibition. One technique available is the tailoring of medication administrations so that it fits in with the family's routine and schedule (Rapoff, 1986; Melamed & Siegal, 1980; Shope, 1981). Medication schedules can be employed to improve compliance. These are a plainly set out form, which details the amount and frequency of medication administrations. The schedules are prominently displayed and act as a reminder to the parents (Voyles, 1983; Spector, 1985; Masek & Jankel, 1982). Other techniques include learning to associate medications with routine activities (Rapoff, 1986; Shope, 1981; Melamed & Siegal, 1980) and using concrete reminders such as stickers on the refrigerator (Shope, 1981). The basis of all of these techniques used to enhance memory and therefore compliance rates is constant encounter, thus decreasing the incidence of forgetting. A further means of increasing remembering is the provision of written material which allows the parent to refer to instructions concerning administration at their leisure (Blackwell, 1979; Shope, 1981). Boyd, Covington, Stanoszek & Coussons (1974) suggest that written instructions can be extended to include a complete explanation of the instructions on medication labels so as to obviate confusion and misunderstandings.

It is suggested by Parrish (1986) that the difficulties with chronically ill children and their families concerning compliance with medical regimens are similar regardless of the exact nature of the condition. This implies that strategies to increase compliance may be generalized across the different paediatric chronic disorders to enhance compliance rates. All of the above described strategies have been proven effective at increasing compliance rates in a variety of conditions and it is suggested that a combination of such skills would be effective with an asthmatic population.

1-2-7 DETERMINANTS OF NON-COMPLIANCE

Explaining low rates of compliance is far from straight forward, Blackwell (1979) suggests that poor compliance is the outcome of the complex interactions between the patient/parent and physician plus the disease process. Meichenbaum & Turk (1987) state that all factors associated with the problem of compliance overlap substantially and none can be viewed as totally independent. There appears little point then in looking for a single factor which determines whether an individual complies with the prescribed regimen. Rather, many factors may impinge on the outcome, working together in complex ways to either enhance or negatively affect each other (Shope, 1981). However, what is possible is that research into the determinants of non-compliance may highlight the contributing factors; factors which may later be targeted for intervention to increase the rate of compliance. These determinants of non-compliance will have differential effects on individuals; some factors may combine to form greater effects on certain individuals whilst not affecting others at all. Presented below are a number of factors found to be associated with non-compliance. They have been combined under two headings; characteristics of the patient / parent and characteristics of the treatment regimen.

Characteristics of the Patient/Parent

(a). *Communication*: The communication relationship between parent and doctor is seen by Weinstein (1985) as a strong predictor of compliance. A poor means of communicating, whether on the parent's behalf or the doctor's, is more than just a barrier; it limits access to health knowledge and skills which ultimately affect the ability to comply. If a parent views the physician as unapproachable then he/she will adopt a passive role in their relationship (Meichenbaum & Turk, 1987). The results of this can be dangerous in terms of not reporting symptoms/adverse reactions to medications or else feeling one cannot contact the physician except in extreme emergencies (Le Baron, Zeltzer, Ratner & Kniker, 1985). Another outcome of this perception of

unapproachability may be unilateral discontinuation of medication and possibly not informing the physician of this. Bruhn (1983) states that compliance is better by mothers who feel their concerns can be expressed to the physician and dealt with in a friendly fashion. This concern regarding the role of satisfaction in compliance is reinforced by Spector (1985) and Meichenbaum & Turk (1987) who state that a parent's satisfaction with their physician can have a direct effect on the rate of compliance. It can be seen that if the parent has a less than adequate relationship with the physician they run the risk of not receiving the degree of instruction and advice necessary to control asthma effectively.

(b). *Errors*: Spector (1985) places a timely perspective on the issue of compliance by stating that patients/parents may well commit errors with respect to medication but most of these are unintentional. Thus the problem is not one of deliberate non-compliance but rather there seems to be number of factors affecting parent's ability to adequately/accurately perform compliance behaviours. Errors in medication administration can be due to a number of factors including forgetfulness and incorrect procedures employed. Remembering to administer medication at the appropriate time and in correct dosage can become a complex task when it is realized that parents are generally busy with family/work commitments at the same time (Pelco et al, 1987). Shope (1981) states that forgetting to administer, misinterpreting the information or incorrectly recalling instructions are the basic problems in non-compliance; a finding which is reinforced by Blackwell (1979).

It appears that the "human" aspects to medication compliance can and do play a large role in non-compliance. Quite often the "fault" is not all with the parent, Chryssanthopoulos, Laufer & Torphy, (1983) found that the labels on the medication containers may be lacking in precise or directive information. Boyd et al., (1974) report a similar finding about the deficiencies of such information. They state that when labels are explicit regarding dosage and administration details a high correlation is found with patient compliance. Possible factors in non-compliance may then be the amount and type of information that the parent has (Le Baron et al, 1985; Boyd et al, 1974; Chryssanthopoulos, Laufer & Torphy, 1983) as well as how the individual is taught this information, thus implicating factors involved with learning e.g. fear, anxiety.

(c). *Demographic Variables*: The one demographic variable which has shown to be somewhat effective in identifying mothers less likely to give advised treatment is the educational level of the mother (Radius et al., 1978; Wood et al., 1985; Becker et al., 1978). It seems that increased formal education is correlated with improved compliance with medical regimens. Radius et al.

(1978) state that the functional aspect of education may serve to increase the mother's sophistication and ability to deal with the child's health. Becker et al. (1978) concurs with this finding and adds that increased education may heighten awareness of the realities of the child's condition and the available treatment's ability to help. Apparently by understanding more of the condition and medications the mothers are more motivated to comply.

Characteristics of the Treatment Regimen

(a). *Complexity of the Regimen:* This refers to a prescribed regimen and its medication components which the parent is supposed to administer to the child. It has been found (Boyd et al, 1974; Voyles & Menendez, 1983; Deaton, 1985; Baum & Creer, 1986; Smith, Seale & Shaw, 1984; Meichenbaum & Turk, 1987; Le Baron et al., 1985; Hindi-Alexander, 1985) that the more complex the demands of treatment then the poorer the rates of compliance. The higher the number of medicines required plus increased numbers of administrations often result in informational and behavioural overloads in those responsible for administration (Meichenbaum & Turk, 1987). When one considers the large number of asthmatic medications available and the variety of modes of administration e.g. oral, inhaled, nebulized, spinhaled and occasionally injected, it is apparent that errors in administration may occur. This is particularly so for the patient who is on several different medications, of different delivery modes which require different dosages at differing frequencies. Hindi-Alexander (1985) suggests that to increase compliance medication regimens need to be as simple as possible both in terms of the amount administered and the frequency.

(b). *Side Effects of Medication:* When a patient is faced with a medication which provokes illness or distressing side effects the probable result is to reduce/cease administration. Such a finding is reinforced by Hindi-Alexander (1985) who found that when faced with undesirable side effects 36% of subjects stopped taking their medication completely or temporarily, a further 32% either decreased the amount they took or skipped doses. It would appear then that any prescribed medication which has undesirable side-effects is going to have an effect on the rate of compliance.

(c). *Duration of Treatment:* Meichenbaum & Turk (1987) state that a consistent finding in their review of the literature is that compliance rates decrease over time. Such a finding is reinforced by Deaton (1985) who found that time since diagnosis is negatively correlated with the degree of compliance. This finding would appear to be particularly relevant to asthma which is a chronic condition with uncertain prognosis and periods of asymptatology. Thus, an asthma sufferer who is on a long-term regimen

and experiences periods of no discomfort due to abatement of attacks, may well reduce his / her compliance with prescribed regimens.

1-2-8 ROLE OF PARENTAL ATTITUDES AND BELIEFS IN COMPLIANCE

The most frequently stated goal of asthma management programmes is the development of self-responsibility for health behaviours, which involves medication compliance (Parcel & Meyer, 1978). A major problem however is assessment of the degree to which intervention has met this goal. In order to help establish the efficacy of programmes, changes in variables such as knowledge and attitudes are often sought. The Health Locus of Control scale is an attempt to operationalize these attitudes and beliefs towards health behaviours, it was developed by Lau & Ware (1981). The scale measures the degree to which an individual perceives events in his / her life as being a consequence of their own actions and thereby controllable (internal control) or as being unrelated to their own behaviour and therefore beyond personal control (external control).

Research has shown there is little doubt that a health related locus of control is significantly associated with a variety of health behaviours and outcomes (Lau, 1982). Belief in self-control over health (internal locus) has a strong positive correlation with actually performing self-care behaviours (Lau, 1982). Support for this finding has been obtained from other researchers. The Health Locus of Control can be used to assess a subject's change in perception of control over health, indicating a readiness to undertake some self responsibility (Hindi-Alexander, 1985). Similarly, Shope (1981) found a significant correlation between parents' health beliefs and their compliance rates and that a large part of the compliance process is due to the parent's perceptions of health. Shope (1981) states that a parent with an internal locus of control over the health of the child may well comply better than a parent with an external locus of control.

Lau (1988) views health beliefs as generalized expectancies concerning health related issues. An internal belief structure on the Health Locus of Control, in combination with a high personal value, of health should predict the demonstration and use of preventive behaviours. Lau (1988) states that in certain situations e.g. being sick, it is probably safe to assume that all people in that situation value health highly. Thus, in a situation such as that of a parent of an asthmatic child it could possibly be accepted that the parent has a high value on the health of / for their child. Support for this assumption comes from Lau (1988) who found the Health Locus of Control subscales employed in the present study to predict an individual's relevant behaviours vis a vis other

people e.g. children. This is as opposed to earlier versions, which predict a respondent's own health behaviours. Thus, if the Health Locus of Control scale can be used to predict compliance with medication regimens, it should predict the parent's behaviours in administering medications to the child. The scale involves four subscales:

- (a). Self Control over Health; Lau and Ware (1981) see this subscale as the efficacy of self-care dimension. High scores on this subscale are associated most strongly with the performance of preventive health-care behaviours. Also, it may be seen as associated with positive attitudes towards the medical system.
- (b). Provider Control over Health; a high score on this subscale is associated with a belief that providers have control over health and also satisfaction with the quality of medical care.
- (c). Chance Health Outcome; this is associated with the acceptance of the role of chance in general health, also a somewhat lower value is placed on health.
- (d). General Health Threat; is associated with perceived susceptibility to a variety of specific diseases and a belief that physicians are unable to diagnose these diseases.

A high score on a particular scale indicates agreement with the subscale as it is named. Someone who scores highly on Self Control over Health would hold beliefs consistent with their personal efficacy concerning health matters. If this is the case, and the person has a high value on health, the individual is more likely to take positive steps to improve or maintain health (Lau, 1988). Conversely, a low score (external) on this scale would distinguish an "at risk" individual unlikely to take personal responsibility for health matters.

It appears that the Health Locus of Control can be used to predict with some degree of accuracy which individuals are likely to comply with medication regimens.

1-3 ASTHMA EDUCATION - WHY IT IS NEEDED

Despite the fact that major advances have been made in the pharmacotherapy of asthma, the level of morbidity and mortality continues at an unacceptable rate (Wilson, 1983). The medical technology for appropriate control of this chronic disease exists and is widely available, yet the level of management is suboptimal (Rachelefsky, 1987; Van Asperen, Jandera, De Neef, Hill & Law, 1986). As noted earlier, the high level of morbidity manifests itself in absences from school, continuing visits to the doctor and admissions to hospital; all of which can affect the development of the child and his/her quality of life (McNabb, Wilson-Pessano & Jacobs, 1986; Buchanan & Van Asperen, 1985). There is evidence that health care facilities are being used more often than 25 years ago (Hilton, Sibbald, Anderson & Freeling, 1982), with asthma accounting for a significant proportion of casualty visits and childhood hospital admissions (Spykerboer, Donnelly & Thong, 1986).

It is possible that for a variety of reasons (e.g. cost of medical consultations, physician errors) some of these children are not under appropriate medical management. However, what is more probable is that control of the condition by parents is not optimal. Spykerboer, Donnelly & Thong (1986) suggest that one reason for this suboptimal management is parents and children having inadequate knowledge. This results in inappropriate management strategies, non-compliance with medical regimens or both. Parents tend to be the primary caregivers and their ability to cope with the children's asthma depends largely on their understanding of the disease. Spykerboer, Donnelly & Thong (1986) state that the majority of acute asthma admissions represent a failure of home management, and that this reflects a lack of parental knowledge. This finding agrees with a New Zealand study carried out in Auckland (Mitchell, Ferguson & Norwood, 1986). A survey of asthmatic patients and significant others carried out by Hilton, Sibbald, Anderson & Freeling (1982) found their general asthma knowledge to be poor, with a significant amount of patients taking inappropriate steps in self-management during attacks. Such findings are not uncommon; Barker (1987) reports one third of his subjects displayed no measureable understanding of the basic nature of asthma, with 38% of the severe and 57% of the mild sufferers not being able to describe early warning signs of severe asthma.

A prime factor in the successful management of an impending asthma attack is the prompt recognition of deterioration in one's condition. However, Ellis & Friend (1985) found the correlation between reports of the functional disturbance and presence of symptoms to be poor in 20% of asthmatics, with a further 20% of their sample being judged to use totally inadequate therapy

during an acute attack. A similar study was reported by Modell, Harding, Horder & Williams (1983) who found a discrepancy between how the patient and / or a caregiver perceived their physical condition and the objective results of the lung function tests. Such lack of understanding must play a large role in the high mortality rate for childhood asthma.

The treatment of asthma relies a lot on the use of inhalers for both relief from and prevention of symptoms, yet the children and their parents are often poorly instructed about this effective form of therapy. Ellis & Friend (1985) found 64% of their subjects displayed faulty inhaler technique. This finding is echoed by Marion, Creer & Burns (1983) who found 25% of their subjects to display incorrect and therefore ineffective use of the pressurized inhaler, and Paterson & Tarala (1981) who found up to 30% of asthmatics fail to synchronized inhaler delivery with inspiration. Medical management available through inhaler technology can only be as successful as the ability of the child or parent to use it properly. Pederson, Frost & Arnfred (1986) state that too often inadequate efforts are made to instruct the child and/or parent and suggest that the simplicity of the device is not a real substitute for careful tuition by an experienced instructor.

Another concern is administration of oral medications e.g. Theophylline. These medications are necessary for the appropriate management of asthma yet the method of administration and knowledge regarding possible side-effects is substandard (Rachelefsky, Wo, Adelson, Mickey, Spector, Katz, Siegal & Rohr, 1986). In fact patients are given little information regarding side-effects from either physicians or pharmacists (Hindi-Alexander, 1985). This lack of knowledge can lead to behaviours incompatible with efficacious therapy. Hindi-Alexander (1985) found 36% of asthmatic subjects stopped taking prescribed medicines either completely or temporarily, whilst another 32% skipped doses due to the unexpected side-effects. These findings are reinforced by Modell et al (1983) who found that up to 50% of patients do not take their medicines in the prescribed manner. The reasons for these misunderstandings may be varied but the common theme appears to be a lack of knowledge. Child sufferers and their primary caregivers ought learn as much as possible about asthma and it's multifactorial management (Shturman, 1984). Such education should be seen as an integral part of routine paediatric health care (Nader, 1985).

The optimal care of asthmatics involves frequent communication between the child, his/her parents and their physician. This allows for the chance to adjust medical regimens and deal with any everyday problems associated with the asthma. However, patients and families have frequently not received all the instructions necessary to comply with the regimen adequately (Marion,

Creer & Burns, 1983). This finding is supported by Hilton (1986) who found that many patients feel that they get too little information about asthma; further, what they do receive may well be delivered under conditions which do not aid memory or recall for the material. Parcel, Nader & Tiernan (1980) put this down to the physicians' attitudes towards education, stating that physicians often relegate a minor role to the tasks of education because of the substantial time commitment required. Nader (1985) estimates that only three out of every ten minutes per paediatric visit is available for education whether this be about the condition, it's prognosis or the use of medications. This possibly results from physicians being primarily trained in the treatment of organic disorders and not in the relevant psychological techniques. Patient load frequently works against indepth education, thus it has been suggested that optimum patient care requires that separate professionals provide joint integrated, multidisciplinary care (Miklich, 1979).

There is a need for education of people with asthma, given the discrepancy between effective medical treatment and the increasing morbidity and mortality rates (Wilson, 1983). Education would allow the parents and their children to assume more responsibility for daily care, encouraging more confidence and the ability to deal with attacks at home and improve ability to comply more fully with prescribed medical regimens. However, to perform this role the parents and their children need information concerning medications, recognition of a worsening condition and mechanisms of the disease (Jenkinson, Davison, Jones & Hawtin, 1988; Parcel, Nader & Tiernan, 1980; Whitman, West, Brough & Welch, 1985; Paterson & Tarala 1981; Van Asperen et al., 1986).

Researchers to date have identified sound reasons for the use of education with asthmatics. However, the literature appears unclear over just what constitutes education. Hindi-Alexander (1985) points out that education programmes which provide children and their parents with both the skills and knowledge necessary to manage asthma appear to offer the best means of improving compliance. As noted above the concept of education (within the literature) is not used in it's pure form of information presentation, rather, it includes training in self-management and compliance enhancing skills. The major implication of this combined education/training skills programme is the difficulty in establishing which is the most effective component, information presentation or training skills. In the following sections it will be shown that asthma education programmes have in fact become bound up with training in skills to behaviourally alter problems. In fact the literature suggests (Parrish, 1986) that clinicians should emphasize specific procedures for parents

to follow to increase compliance, in addition to the provision of information regarding the condition.

1-3-1 DEFINITION OF EDUCATION AND SELF-MANAGEMENT

The education process for asthmatic children and their parents deals with the provision of accurate and understandable information concerning the disease, its treatment and other health related matters. A primary part of this education is the need for self-management by the children and the parents. Hindi-Alexander (1985) defines self-management education as being a process wherein people with various health problems learn to work with health care providers to help themselves, thereby enhancing therapeutic intervention. Thus the idea of patient education is that the individual be able to do something concerning his/her condition in addition to knowing about that condition (Nader, 1985). Ideally education then is viewed (within the literature) as involving a combination of learning experiences concerning knowledge and behavioural skills, which together will allow behaviours to be altered. Knowledge concerning asthma and its attendant problems is undoubtedly essential to good management but it is also necessary to have a series of skills to implement such knowledge (Hindi-Alexander, 1985).

Education is not simply a matter of providing a few facts when the health care provider decides. Often the patient is not ready to learn when the health care provider is ready to teach, or perhaps he/she is not sufficiently motivated. Thus, good education will take account of the client's needs and abilities; with the information being presented in an easily comprehended manner. Wilson-Pessano & McNabb (1985) suggests that the exact nature of the education needed will be mediated by a number of factors related to patient characteristics. Such characteristics are likely to include the severity of the condition as well as the patient's physical and social environment. Other considerations will be the patients' level of intelligence and attitudes / beliefs.

The education process can take both formal and informal approaches with the former suggesting organized programmes whilst the latter can comprise any explanation concerning the condition, treatment and medicines and / or the modification of associated behaviours. Informal education is best characterized by the primary information asthmatics receive during the initial diagnosis period. Thus, in one sense all asthmatics will have received a modicum of education at least. Such education generally takes the form of instruction by the health care provider on the nature of asthma and the treatment plan. Topics covered briefly may include the medication, environmental control and symptom management. In paediatric health care

such primary education is typically delivered to the parent or main care-giver. The next step or secondary education component will be ongoing instruction received during regular consultations or at times when complications may arise. These first two levels of education are usually sufficient for a number of patients where the asthma is relatively mild, easily controlled and the parent or family is sufficiently motivated and capable of taking responsibility for self-care. (Wilson-Pessano & McNabb, 1985). However, there is another group which often requires a more structured level of education, these are the families with more severe asthma and others who experience difficulties in managing the condition e.g.. young children. This "tertiary" type of education is no longer of a strictly preventative nature but rather is geared towards remedying chronic management problems i.e.. by a mixture of information presentation and behavioural skills.

The term self-management education is used to describe programmes which employ a number of educational and behavioural change strategies. The education experiences are designed to promote a change in behaviour which will lead to improved health states, thus enhancing the quality of life (Wilson-Pessano & McNabb, 1985). These educational programmes typically involve the learning of facts about the problem, understanding all the factors which affect it and most importantly, developing the skills necessary to achieve control over symptoms (Hindi-Alexander, 1985; Hilton, 1986). The underlying aim of self-management education is that the participant will become better motivated and develop increased responsibility for his / her condition. This, allied with information concerning the pathologic condition and it's treatment will allow each individual to make appropriate decisions concerning their asthma. Most asthmatics and their parents are, with education, able to eventually accept the changes in their bodies and it's functions due to the asthma. If not they probably will not learn to care for themselves (Gilmartin, 1986). Thus, self-management education can be viewed as a means to strengthen the individual's involvement, determination and self help concerning the control of asthma.

1-3-2 AIMS AND GOALS OF EDUCATION PROGRAMMES

Although asthma programmes may differ in their length, content and degree of complexity, they all have a common goal within the education literature. This is to assist the participant in developing improved management skills which will both prevent and enhance the treatment of asthma (Feldman, 1987). The major issues are appropriate decision making on the part of the patient or parent (Feldman, 1987 ; Bartlett,1983; Lewis & Lewis, 1987) whilst promoting a sense of self-responsibility. Thus the participant is

given a measure of control concerning treatment which involves assuming an active role in the decision making process rather than relying on the healthcare provider to deal with everything. One result of self-management training is the ability to resolve problems associated with asthma rather than immediately seek medical advice. Effective solutions for predictable problems would have been learned during the education process. Training in such decision making skills results in an activated patient who has gained the ability to analyze, evaluate and synthesize information (Bartlett, 1983). The individual must be able to weigh up the problem and consequences of various courses of action. Thus, it can be seen that decision making is a skill, rather than the simple memorization of health facts. This lends support to the notion that the term education, as used in the literature, refers to a combination programme rather than just presentation of information.

The second major goal of asthma education and self-management planning is the increased patient compliance with prescribed medical regimens. Non-compliance is complexly determined but lack of comprehension of requirements is a major factor. Education offers the chance for each participant to learn and understand more fully, not only how to take each medicine but also how they work and why they need to be taken. Any increase in compliance increases the control of symptoms associated with asthma and ultimately decreases attack frequency and severity.

Increased compliance and self-management skills enhance the quality of life for the sufferer. Asthma education allows the minimizing of interference in the patient's activities, whilst decreasing the adverse impact on lifestyle (Wilson- Pessano & McNabb, 1985; Feldman, 1987). Other aims are the decreased use of emergency facilities (Feldman, 1987), reduced morbidity and school absences (Lewis & Lewis, 1987) as well as reduced family stress, whilst increasing independence with respect to the health care provider (Wilson- Pessano & McNabb, 1985).

1-3-3 THEORY IN ASTHMA EDUCATION

Social learning Theory

This theory states that behaviours which humans exhibit are partly determined by rewards or punishment previously experienced. The patterns of behaviour exhibited may be acquired by direct experience or by observing the responses of others. The success or otherwise of each response will lead the individual to select the most favourable behaviours, in terms of consequences.

The important contribution of social learning theory regarding this choice of behaviours is the emphasis placed on cognitive processes. These refer to the ability to think and represent situations symbolically, thus allowing humans to foresee the probable consequences of actions and alter behaviours accordingly (Atkinson, Atkinson & Hilgard, 1983). Individuals do not have to directly experience the effects of a particular action to be aware of the consequences, it is possible to learn by observation i.e.. viewing others model behaviours and noting the consequences. Thus, individual differences in behaviour result in a large part from the differences in kinds of learning experiences encountered in the course of maturation. These can be either due to direct or observed experiences.

The assumption of social learning theory is that individuals will behave in ways likely to produce reinforcement for their actions. Atkinson, Atkinson & Hilgard (1983) state this in terms of a specific action which is chosen in a given situation will depend on the expected outcome i.e.. reward or punishment. Here, the individual's appraisal of the situation, past reinforcement history plus characteristics of the situation are important. Different reactions to a given situation will be due, in part, to differences in cognitive aspects and learning experiences. Thus, an individual's expectancies regarding the performance of certain behaviours will guide his / her choice of whether to implement it and his / her feelings about abilities to complete the task.

Hindi-Alexander (1987) suggests that asthma education programmes tend to be based on social and behavioural theories which assume the patient is a passive partner in the care of asthma but can be activated to become a participant in healthcare.

The concepts which form what has come to be termed self-management are embedded in behavioural and social learning theory (Creer, 1987). Theorists such as Bandura, Mischel and Thoresen suggest that the cognitive, physiological, environmental and behavioural aspects of asthma should be considered together in order to achieve maximum educational benefit which can be translated in to skills to be performed when necessary. It is this performance of appropriate behaviours, either preventive or relieving, which is the crux of self-management in asthma. The behavioural aspects involve the observation and definition of problem areas as well as affording the techniques to use in the treatment plan. This allows the transformation of learning into performance.

Social learning theory provides a means to understand the cognitive processes within the individual which permit an individual to perform a new behaviour or continue to exhibit a previously learned one (Nader, 1985). Examples of such cognitive processes would be appraisal of the situation,

attention to the behaviours modelled, retention of the consequences and decisions concerning self-efficacy expectations. Social learning theory offers most to asthma education designs because it highlights the interactions among the cognitive structures of the individual, the behaviours to be mastered and the environment this must occur in. It also allows educators to consider an important variable within the education equation; this is an individual's feeling of self-efficacy (Nader, 1985) or the confidence in one's own ability to perform a behaviour. This self-efficacy construct mediates between the cognitions and behavioural changes. Each individual will have certain expectations concerning his / her ability to successfully perform a given task. These expectations will determine whether the coping behaviours in asthma attacks etc. will be initiated, how much effort will be expended on the behaviours and how long this effort will be sustained in the face of obstacles e.g.. worsening attacks. Bartlett (1983) suggests that social learning theory provides the asthmatic individual or his/her parent with three ways to influence self-efficacy expectations. These are : the successful performance of a given behaviour will increase one's confidence in the ability to repeat that performance, by observing a credible role model exhibit the behaviour and by providing encouragement and positive feedback for performance. Thus an asthma education programme which employs these concepts will have more chance of raising and/or maintaining the positive expectations for self-efficacy. These expectations are necessary to perform the self-management behaviours central to dealing with an attack.

In accordance with social learning theory, Creer (1987) states that the performance of such behaviours involves the appropriate synthesis of the cognitive, physical, physiological and behavioural variables concerning an asthma attack. In order to manage an attack the sufferer must be aware of physiological changes in his / her body and be able to discriminate symptoms which indicate an attack is imminent (cognitive). For this discrimination to take place the education programme should offer appropriate knowledge concerning the precipitants. Following on from this if the sufferer has ready access to this knowledge and associates it with an imminent attack then the chances are higher that his / her self-efficacy expectations will be increased, thus improving chances of applying self-management skills. Thus social learning theory offers a framework to work within concerning the provision of asthma education. It allows variables such as expectancies, comprehension and performance to be accounted for, which in turn offer a more effective means of disseminating information in order to promote self-management.

1-3-4 CONTENT OF ASTHMA PROGRAMMES

The aim of any asthma education is obviously to share information but more importantly it is to ensure that what information is offered will be understood and applied by the recipient. Thus it is crucial that any programmes must be well organized and presented in terms appropriate to the target audience e.g.. the length, language used. If, as is usual, the time factor and available resources are limited then priorities must be set concerning the importance of various aspects of the content. Hindi-Alexander (1985) suggests that the structure and organization should be conducive to the acquisition of knowledge and understanding of asthma. Material should be presented in a manner which allows the development, performance and retention of competent skills. It is important to appreciate that education involves more than the mere exchange of information regarding the asthma and its treatment. Research indicates that simply giving information and increasing one's knowledge about the illness and treatment is necessary but often not enough to increase compliance with medical regimens (Meichenbaum & Turk, 1987). Thus, it is important to account for other variables when designing a programme, these include the patient's motivation and the rationale for the importance placed on behaviours. The content for any given programme will depend largely on the target audience but also on the specific aims e.g.. increasing knowledge, compliance with medication, decreasing hospitalizations etc. The following description of possible content would fit well into any general education programme but is suggested with the goal of increasing medication compliance in mind. The suggested content deals with the provision of a package as put forward by the literature to date i.e.. a combined education and training in skills package, rather than an information presentation package alone.

One of the most important aspects to be addressed, possibly in the first session, is the feelings and beliefs of the parent or child concerning asthma and associated problems they are experiencing (Nader, 1985; Lewis & Lewis, 1987). It is essential that the individual be permitted to express what it is like for the family to experience asthma, how it affects them and tell of any associated fears. In addition, by asking each person to tell their beliefs concerning asthma, its causes, prognosis, treatment efficacy etc., the educator can obtain guidelines for needed content e.g.. to correct any misconceptions or negative attitudes held towards asthma. Meichenbaum & Turk (1987) feel it is crucial that educators look at the nature of the patient's expectations concerning the disease plus their role and responsibilities within it. It is these very attitudes and beliefs which may be affecting the individual's compliance rate with prescribed medication. By addressing the individual's concerns throughout

the programme, as well as correcting inaccurate and possibly dangerous beliefs, the educator is in a position to perhaps modify the individual's thinking concerning the asthma.

Whilst every programme should include discussion concerning the pathophysiology of asthma, Meichenbaum & Turk (1987) state that correct information concerning the disease itself is only weakly related to clinical outcome of asthma. What is needed is an understanding of the triggers which may precipitate an attack within a given individual (Mitchell, Ferguson & Norwood, 1986; Nader, 1985; Lewis & Lewis, 1987). Armed with this knowledge concerning why certain things precipitate attacks the parent is then in a better position to actively alter behaviours which may promote exposure. The essential component that completes the knowledge and permits its translation into behaviours is the promoting of decision making skills concerning what and how to avoid particular triggers. This decision making is seen in the development of self-management strategies which are offered from within the programme. These strategies take the form of deciding what to do about the triggers, whether to avoid them, eliminate them or pre-medicate the child when exposure is imminent (Hindi-Alexander, 1985). This in turn facilitates a form of mastery regarding symptom control which is the essence of self-management (Hindi-Alexander, 1985).

Allied to this increased knowledge of triggers is the importance of providing general living skills and behaviours which promote good health. Included in this information should be the need for a good diet, the benefits of relaxation and the importance of fitness and exercise (Hindi-Alexander & Cropp, 1984; Rakos, Grodek & Mack, 1985; Kohen, 1985). The emphasis should be on self-reliance and self-care techniques (Lustig & Groothuis, 1984) which enable the parent to promote a lifestyle and activities which are beneficial to the management of asthma. It is promotion of sound basic living which augments medical treatment and ensures complete attention to the condition and its management.

Perhaps the central aspect to education programmes, and especially relevant to the task of increasing compliance rates, is the provision of knowledge concerning medicines. However, as Meichenbaum & Turk (1987) point out, simply increasing a person's knowledge concerning medications does not lead automatically to an increase in compliance rates. This will only occur if the individual is also instructed in ways to implement this new found knowledge within the treatment regimen. The important knowledge concerns behaviours about how to administer the medicines correctly, appropriate times and what to do if problems occur. The information should be accurate and include detailed rationale for the taking of each type of medicine, plus its

purpose and how it works. Of particular importance is the function of each medication, especially the difference between the relievers and preventers so that the individuals are sure of which to take and when. Also needed is information such as the time specific medicines take to work and any associated problems. Meichenbaum & Turk (1987) suggest an important aspect of education is the provision of simple information sheets detailing the above facts. By presenting adequate knowledge concerning the role of each medicine it is anticipated that the individual will become aware of the correct medicine to take for a variety of problems. Thus, armed with this knowledge one can self-medicate according to varying needs and therefore can handle a worsening situation (Hindi-Alexander, 1985). The intention is for the sufferer or the parent to handle attacks correctly and confidently at home, rather than seeking medical attention before it is actually required.

One aspect of medications which causes parents a great deal of concern is the possibility of side-effects from medication. The most common fears deal with the effects of steroid medication on the child's growth pattern, drug dependency and future health. These fears are legitimate for the family and must be addressed professionally, both to allay fears and clear up misconceptions. If a mother is worried that administering steroids may harm her child or if she encounters unexpected side-effects she will most probably reduce the amount administered or even prematurely finish the course (Meichenbaum & Turk, 1987). By offering information concerning the possible side-effects of medications within a group setting it is possible to reduce the level of fear or suspicion experienced by the parent. Further, the group can act as a source of support by both reducing the sense of alienation / isolation felt and offering positive coping strategies. These group coping strategies can be used to build upon and reinforce methods already planned for the programme. Meichenbaum & Turk (1987) suggest that any session dealing with side-effects of medication should, after promoting self-efficacy concerning coping skills, follow through with a review of the therapeutic benefits of treatment.

Although the aim of asthma education is self-management, it is not suggesting that people attempt to deal with all aspects of asthma alone. It is still essential to have regular consultations with the family's own general practitioner. However, this experience can often be less than satisfactory for the family. Research indicates that patients feel their physicians often appear unapproachable, act too busy for them and use too much medical jargon; whilst not clearly explaining the condition, its medication and prognosis (Meichenbaum & Turk 1987). The task for the educator is to deal with these problems and offer skills to the parent or sufferer so better communication can be effected. Foremost, is to show the parent that dealing with asthma requires a

partnership between physician and parent, rather than a one sided dominating role by the physician. Allied to this awareness of being an active partner is the need for the parent to learn assertiveness skills. These skills will allow the parent to express her concerns, fears, dissatisfactions and suggestions concerning the child's condition and treatment. One of the major problems concerning compliance is that the parent does not understand what is required, in terms of administering medicines. This can be due to a variety of reasons ranging from nervousness to the type of language employed by the physician. Unfortunately, Meichenbaum & Turk (1987) point out that parents rarely tell their physician when they do not understand and are reluctant to ask too many questions, for fear of being viewed as ignorant. It is anticipated that by providing a new view of the parent's true role in asthma care, in conjunction with assertiveness skills, problems associated with communicating with the physician can be reduced.

In order to implement the learned behaviours and fully realise the role of self-management, the parent must experience a high level of comprehension but also be able to recall the correct information when it is required. It is imperative that the individual remember that some action needs to be taken, what the specific action is and then implement it correctly. Meichenbaum & Turk (1987) state that patients with accurate recall of instructions have a compliance rate up to three times that of patients who experience one or more errors in recollection. Thus an education programme should include a section dealing with the mechanics of memory, factors which interfere with learning and also provide skills or knowledge to improve memory. To enhance this further, the entire programme should be organized in a fashion commensurate with this idea. Material should be specific and clear with important information being repeated. Further, concrete illustrations should be employed to enhance clarity as well as the use of written material and handouts to augment oral presentation (Meichenbaum & Turk, 1987). Behavioural skills should be presented which offer practical means to overcome the problems of forgetting. Examples of this may include the use of mnemonic devices, direct cues such as leaving medicines by the toothbrush or indirect ones such as reminders taped to a clock. These cuing procedures can help improve compliance with medical regimens by being highly visible and becoming associated with specific medications or by being paired with a given routine.

1-3-5 CONDITIONS WHERE EDUCATION HAS EFFECTIVELY BEEN EMPLOYED

Education has been used throughout the years in attempts to instruct the general public about health hazards and help improve the quality of life for sufferers of a number of conditions. As early as the 18th century the general public was being exhorted to understand and identify dangers associated with both giving birth and the raising of children. Such attempts at education warned parents about the dangers of uncovered wells as well as teaching general principles of child health e.g. benefits of regular exercise and opening windows for fresh air (Nader, 1985). It can be seen that attempts to promote health and prevent disease among the public and specifically children are not recent ideas but longstanding. Later forms of education involved primarily the provision of information concerning the dangers of contracting diseases and their consequences e.g. tuberculosis (Hilton, 1986). This education, coupled with mass immunization programmes, proved to be effective in lowering and sometimes eradicating such diseases. Other early, and successful, forms of education involved providing the public with facts about conditions and promoting awareness of preventative measures such as immunization programmes for polio and whooping cough (Hilton, 1986).

Towards the middle of the century the areas of medical concern for education shifted from the acute problems to the prevention and treatment of chronic illnesses. These education programmes have demonstrated one approach to increase a patient's management of chronic conditions especially haemophilia, heart disease and diabetes (Rakos, Grodek & Mack, 1985).

Juvenile Diabetes: This condition has been looked at closely by both behavioural scientists and health educators (Mullen & Mullen, 1983; Nader, 1985). One of the central difficulties with diabetes is the long and complex regimen the patient is required to follow in order to control the condition. This involves a good degree of learning on the patient's part tied closely to adhering to a strict diet both in terms of content and quantity. In order to determine the level of insulin injection to be administered, the patient must be able to collect and analyse samples of urine several times per day. Thus it is necessary for the child to be constantly vigilant to his medical needs so as to avoid hypoglycaemic states. Education has been used effectively with parents of very young diabetics, as it is the parent who must bear the primary responsibility for medical management of this condition (Schwartz & Johnson, 1985). It is necessary for the parent to be aware of the course and possible complications of the disease so as to handle the child's questions and emotional reactions. Material included in programmes to date includes: information regarding the condition and its effects, self-monitoring

techniques concerning performance of behaviours and training in self management skills e.g.. analysing urine. Thus, it is apparent that the programmes are a combination of both education and behavioural skills training.

Type A Behaviour: Sufferers experience significantly more coronary morbidity and mortality than patients without the same characteristics. These characteristics include appearing aggressive and hostile, self-imposition of unrealistic and frequent deadlines and a chronic sense of time urgency. Education programmes used in this area aim to change the lifestyle of the patient by providing information regarding the possible outcomes plus teaching relaxation and stress management techniques. A series of skills are taught to improve management of time and how to leave/avoid stressful situations. A review of the literature has showed a significant decrease in serum cholesterol compared with controls (Bellack, Hersen, & Kazdin, 1985).

Peptic Ulcer Disease: One of the factors in the development of this disease in patients is the presence of stress. The provision of knowledge concerning feedback techniques (to heighten awareness of internal stress levels) and training in their application have effectively been employed. This information and training has been shown to alter the production of gastric acid secretion in patients suffering from Peptic ulcers (Bellack, Hersen & Kazdin, 1985).

Hypertension: The use of education, which included both information and skills training, has been shown to directly improve compliance with medications prescribed, thus altering the level of personal control concerning hypertension (Goldstein, Green & Parker, 1983; McHatton, 1985). Such programmes have resulted in a decrease in the use of acute care services allied with an increase in health status and functions (Mullen & Mullen, 1983). The content of these programmes has varied depending on their setting but one of the most effective programmes involves the provision of facts about the condition and specific skills training such as relaxation to the person with hypertension. Such training has lead to post treatment effects of up to a 10% reduction from baseline in systolic and diastolic blood pressure (Bellack, Hersen & Kazdin, 1985).

Other medical conditions where education programmes have been used to varying degrees of success include : Cardiac rehabilitation (Miller, 1985;), Otitis Media (Nader 1985) and Headache treatment (Bellack, Hersen & Kazdin 1985).

One of the major health areas concerned, deals with the modifying of people's dietary habits. Nader (1985) reports significant differences between treatment and control groups concerning the consumption of high-sodium and high-saturated fats foodstuffs, after participating in an educational

programme. In this case social learning theory was employed to get entire families to improve their diets and increase physical activity. Thus again the programmes involve both information and skills training to alter behaviour. Fureyt, Scott & Giotto 1979 (cited in Bellack, Hersen & Kazdin, 1985) compared diet programmes involving a) use of a diet booklet alone b) nutrition education alone and c) behavioural interventions coupled with nutrition education, to reduce plasma cholesterol and triglycerides. They found that at six months follow-up the subjects in the behavioural plus nutrition education condition had a significantly greater decrease in cholesterol than the other conditions.

Perhaps the most common (and lucrative) area of education is the parent-training manual arena. These manuals supply parents with knowledge about acceptable behaviour patterns and a variety of behavioural skills to use in rearing their children. The idea is to allow parents to deal with the child's short term problems and also to prevent the development of future serious problems. Although no accurate figures are available concerning the success of these manuals Bellack, Hersen & Kazdin (1985) report such programmes to have met with generally favourable success from the public.

1-3-6 FINDINGS CONCERNING EDUCATION PROGRAMMES WITH ASTHMA

The results of education programmes with parents and sufferers of asthma have generally been favourable. However, a note of caution needs to be sounded concerning the adequacy of evaluation of some of these programmes. Problems in this area concern the short duration of follow-up for some studies (Van Asperen et al., 1986), the limited sample size (Whitman et al, 1985) and the lack of valid control groups in others (Whitman et al, 1985; Hindi-Alexander & Cropp, 1984). Another point to be aware of is the significance of results as they relate to differing types of asthma. The potential for improvement is higher for a severe asthmatic with minimal understanding of the condition as opposed to a mild case with a high level of knowledge. Thus it is clear that any evaluation needs to include both pre and post test measures of knowledge levels and morbidity rates regarding severity types (Hilton et al, 1982). Typical measures employed to evaluate asthma education programmes are : level of asthma specific knowledge, school absences, visits to the doctor and accident and emergency services and number of hospitalizations plus peak-flow recordings of lung function (Van Asperen et al., 1986; Taggart, Zuckerman, Lucas, Acty-Lindsey & Bellanti, 1987; Hilton et al 1986; Clark, Feldman, Evans, Wasilewski & Levison, 1984; Mitchell, Ferguson & Norwood, 1986).

Knowledge

The level of a subject's knowledge is a widely used measure to detect any changes due to intervention. Prior to intervention, then again at varying stages following it, the subjects are given a test concerning asthma, its causes, triggers and effects. Results regularly show an increase in knowledge between pre and post test evaluations, the majority of which are statistically significant when compared with control groups (Van Asperen et al, 1986; Hilton, 1986; Goldstein, Green & Parker, 1983). Parcel, Nader & Tiernan (1980) found that education programmes improve asthma knowledge of both parents and children, reinforce a more internal health locus of control concerning asthma and further brought about a decrease in illness anxiety. Hindi-Alexander & Cropp (1984) concur with this finding concerning a change in the health locus of control towards a more internal self-control. They suggest this indicates a favourable change in attitudes and self-confidence as the patient's perceptions of asthma gradually change. This is possibly brought about because the patients are able to see that they can influence the course of their asthma. Parcel, Nader & Tiernan (1980) feel that the increased understanding by children about their asthma influences their ability to take a more active role in health care, by allowing them to feel more confident concerning self-management. There is sufficient evidence to establish that education programmes do increase knowledge concerning asthma; however, Hilton et al (1986) caution that this should not be the only aim of education programmes. They found that solely attempting to increase a subject's knowledge concerning asthma manages to increase the patient's satisfaction, however, there was no carry over effect of this increased knowledge regarding the level of subject's morbidity at the twelve month follow up. It appears then that knowledge alone does not improve health status.

Morbidity

One of the major concerns for any asthma sufferer and his/her family is the number of attacks the individual suffers. These may range from the mild episodes requiring increased medication, through the need to visit a physician's surgery, visits to accident & emergency or even hospitalization. Each episode, whatever the severity, has effects on the child by disrupting his / her normal activities. Combination education programmes have been found to have a positive effect on the child's life by decreasing levels of morbidity and thus allowing a relatively normal existence (Hilton, 1986). The participation in organized programmes which promote self-management skills has led to a reduction in the severity of attacks (Taggart et al, 1987; Modell et al, 1983) and also in the frequency of attacks experienced by the children (Taggart et al, 1987;

Modell et al 1983). This demonstrates clearly that programmes involve more than just the provision of information. A flow on from participation appears to be a general reduction in the number of non-emergency medical visits as well as a drop in the number of emergency room visits (Hilton, 1986; Goldstein, Green & Parker, 1983; Mitchell, Ferguson & Norwood, 1986). The advantages of this appear in reduced expenditure on medical bills, less time off school and it also indicates an improvement in the children's health. Mitchell, Ferguson & Norwood (1986) found that providing an intensive programme which taught self-management skills to children and parents was effective in reducing admission to hospital, when compared to the control group.

It appears then that providing organized programmes with defined goals, which include information and behavioural skills training will lead to a reduction in the experiencing of attacks and associated problems. Such combined programmes have the ability to significantly increase the level of self-management behaviours associated with an asthma attack. However, the greatest reduction in healthcare use following exposure to a combined education programme is amongst families with prior experience of hospitalization and high baseline levels of accident & emergency use (Rakos, Grodek & Mack, 1985). Thus it seems that the more severely affected asthmatics may possibly benefit greater from education. This is possibly because they have more to learn concerning the condition's medication or perhaps the experience of hospitalization may focus the families attention on the information and skills being presented in the education programme. Thus, the experience of hospitalization may well increase motivation to comply or at least learn about the condition and management skills. The idea that more severe asthmatics benefit more from combined education is supported by Hindi-Alexander & Cropp (1984) who suggest that education programmes may have more effect on children with moderate to severe asthma rather than on those with mild episodic asthma. Although there is a greater reduction in healthcare use amongst more severe asthma sufferers, any real decrease in morbidity must result in a better quality of life for the child concerned and also for the family in terms of reduced medical bills (Lustig & Groothuis, 1984). This finding is particularly pertinent to contemporary New Zealand, when one considers the present cost of doctor's consultations and the recent increase in prescription charges.

School Absences

The findings within this area are less clear cut than for knowledge and morbidity, due in part to the subjective nature of some measures employed

e.g., school related problems. However, it is suggested that the findings offer some indication of the possible relationship between education and school absenteeism. As has been stated earlier, the continued experiencing of asthmatic attacks will lead to increased time off school and associated difficulties in academic performance and social behaviours (Siegal & Rachelefsky, 1985). Such experiences will have effects on the development of the child and interfere with normal advancement. The knowledge and skills provided by education programmes have a positive effect on reducing the rate of school absenteeism (Goldstein, Green & Parker, 1983) and has been shown to have a favourable impact on school related problems (Clark et al., 1984). The children in this study (Clark et al., 1984) were found to maintain a better academic performance when compared to a control group. Furthermore the children were found to manage better and also showed increased attendance at gym classes compared to the controls. These findings are confirmed by Rakos, Grodek & Mack (1985) who found that education programmes can benefit all children (by reducing absenteeism) whether their asthma is mild or severe. They state that education programmes increase self-management skills in children whilst also improving both school performance and adjustment. Reduced absenteeism will have the effect of allowing asthmatic children to remain at a par with their peers and reduce the interference in what is a significant developmental and learning period in the child's life.

A finding which should be mentioned in this context is that of Whitman et al (1985) who found that all participants in their study displayed decreases in morbidity. Both experimental and control groups made daily recordings of asthma episodes whilst only the experimental group received an education programme. Whitman et al (1985) suggest that participation itself was as effective in decreasing asthma problems as was being part of the experimental group. The experimental group showed gains in both knowledge and asthma related skills above those of the control group. Whitman et al (1985) suggest that family record keeping and general involvement in asthmatic monitoring may be important in affecting attitudes and behaviours towards asthma. This is due to an increasing awareness of the need to administer medications correctly. The resulting prophylactic effects are manifested in decreased morbidity.

Although it appears that not all education findings are significant or conclusive e.g., Whitman et al. (1985), it is suggested that the results to date are encouraging enough to suggest that asthma education has a role to play in promoting improved health. The benefits appear in a decrease in the disruption caused by asthmatic episodes, reduction in financial burdens as well as lessening family stressors. Parcel, Nader & Tiernan (1980) state that

more direct involvement of children and / or parents in the healthcare process and the placing of greater emphasis on self-management will result in major benefits for all concerned.

1-3-7 REVIEW OF MAJOR ASTHMA EDUCATION PROGRAMMES

Over the years there have been a number of programmes developed for use with a variety of populations, in differing settings. Programmes vary regarding the severity of asthma, social and ethnic backgrounds and languages of the target population that they address. These programmes, in their various forms, are not without their criticisms. One of the most fundamental flaws is the use of comparison groups which have differing baselines concerning the severity or incidence of asthma. Such a problem makes it very difficult to evaluate the worth of the programme. Other problems in evaluating the outcome are lack of suitable control groups, biases in subject selection and unreliability in outcome measures concerned. However, Wilson-Pessano & McNabb (1985) states that there is now a sufficient accumulation of evidence to suggest that many of these programmes can make a significant contribution to decreasing problems associated with asthma.

As has been stated earlier, the basis to most education packages is that of the social learning approach and its emphasis on cognitive/behavioural interventions. Although all programmes will differ in the emphasis placed on cognitions, behaviours, attitudes and beliefs, these things can all be found to some degree within the majority of education programmes. Thus, the aim, whatever the target population and setting, is to provide information and attempt to change attitudes and beliefs as well as promote self-management behaviours (Thoresen & Kirmil-Gray, 1983). One of the earliest forms of "education programmes" took place within a residential placement setting whereby nonresponsive, chronic asthmatics stayed for up to six months or longer in a hospital type environment. This permitted the monitoring of the disease over time and the opportunity to deal with associated stress, whilst offering a degree of control e.g. compliance with medical regimens (Wilson-Pessano & McNabb, 1985; Blessing-Moore, Fritz & Lewiston, 1985). However, there is contention as to the amount and value of the education component within residential placements as compared with the supply of comprehensive treatment. An offshoot or refinement of this idea is the summer camp for asthmatic children; these are held over one or more weeks in a holiday camp atmosphere. Children live in for the duration and participate in a variety of physical/recreational activities as well as attend activities/classes designed to promote asthma knowledge and behaviours. The most well known of such programmes is "Camp Wheeze" which began in the United States in 1970.

They report success in decreasing doctor's visits, reducing school absenteeism as well as the parents reporting their children's condition to have improved following participation. However the claims are for a study which did not have a control group, thus the findings could well be due to seasonal changes (Wilson-Pessano & McNabb, 1985). Other settings where differing programmes have produced improvements on a variety of measures are with community groups, medical offices and clinics (Wilson-Pessano & McNabb, 1985), school groups and general public via media campaigns (Blessing-Moore, Fritz & Lewiston, 1985). Rachelefsky (1987) states that these programmes have shown that basic, essential information can be delivered to asthma sufferers thus influencing the attitudes, behaviours and motivations of those afflicted.

Those involved with asthma education agree that education should be available as widely as possible. Thus efficient dissemination of the information and relevant programmes is important. The most efficient and cost effective means of achieving this is accepted to be by the use of standardized, packaged programmes based on social learning theory (Feldman, 1987). Thus with the publishing of reliable and validated programmes in easily accessible packaged form, it is now more possible than ever to achieve improved knowledge in behaviours on a nation-wide basis. In fact, Wilson-Pessano & McNabb (1985) suggest that the attention given to developing asthma programmes has resulted in a body of experience which can be generalized to patient education in other medical conditions. The majority of package programmes have been reviewed elsewhere (Rachelefsky, 1987), and therefore this paper will present only a brief review of the findings of the four most widely accepted programmes. This includes the "Open Airways" (1984) package which was employed in the current study.

Super Stuff

This package is designed to be self administered by seven to twelve year old children. It is presented in developmentally appropriate terms and consists of activities for the child to become involved with which are designed to promote asthma understanding. The self-management focus is on asthma facts and fallacies, internal/external signals and triggers plus personal control and decision making (Rachelefsky 1987). Findings show modest benefits in the management skills of moderate to severe asthmatics. However, there was no differential effect on the level of severity of attacks or number of medical contacts. Other findings were an increase in asthma knowledge and a marginal impact on school absenteeism (Rakos, Grodek & Mack, 1985; Wilson-Pessano & McNabb, 1985).

Asthma Care Training (ACT)

This programme has been developed for use with parents and their asthmatic children aged seven to twelve years. It employs the analogy of "you're in the driver's seat", to promote the idea of being in control of health as being similar to driving a car. Symptoms and medications are presented as being equivalent to the colours of traffic lights. Thus, green activities and symptoms suggested it is OK to continue as you are, whilst red symptoms suggest it is time to stop activity and take the appropriate colour coded medication. Parents and their children were interviewed at three, six and twelve months after treatment to assess changes in knowledge, morbidity, attitudes etc. Findings show that both the experimental and control groups increased their asthma knowledge. Only the experimental group however, self-reported a significant change in compliance and significant decreases in emergency room visits and days hospitalized (Rachelefsky 1987; Wilson-Pessano & McNabb, 1985).

Airpower

This programme was developed over a number of years by the researchers who employed the critical incident technique. This enabled them to find out just what it was that young children did during an attack and were actually capable of. The programme involved the presentation of basic asthma information, group discussion of this information and problems associated with asthma as well as the teaching of relaxation training. The findings show significant post treatment differences for the experimental group on measures of the child's independent self-management behaviours, as reported by parents. The improvement was found to be greatest on those behaviours specifically taught, such as what to do when breathing becomes worse. However, Wilson-Pessano & McNabb (1985) reports that there were no significant changes on other health outcome variables.

Open Airways

This package provided the basis for development of the content for the Education condition within the present study. Feldman & Clark (1981) developed the programme based on their interviews with 290 asthmatic families concerning their asthma related management behaviours. The hypothesis being that participation in the programme will increase both the child's and parent's ability to manage asthma. Stated aims of the programme are to decrease visits to the doctor and hospital, reduce school absenteeism and lessen disruption to family life. Each one hour session deals with a particular aspect of asthma management including; medications, making decisions about

activities, communication with doctors and general information. At twelve months following intervention 73% of participating families were reinterviewed concerning their visits to doctors, school absences and grades obtained; in addition hospital records were viewed. Amongst children who had one or more hospitalizations in the year prior to intervention there was a significant reduction in hospitalization and emergency room visits when compared to a control group (Wilson-Pessano & McNabb, 1985). Further, the parents in the experimental group displayed a significantly greater increase in the steps taken to manage an attack than controls. Kaplan, Rips, Clark, Evans, Wasilewski & Feldman (1986) report that in a later study the programme also had a significant impact on the self-management skills and school grades of experimental group children.

1-3-8 SUMMARY OF EDUCATION PROGRAMMES

The above section details the efficacy of education programmes (as defined in the literature) in addressing problems associated with paediatric asthma. However, the key point is that such programmes do not actually represent education packages, rather they are a combination of information presentation and training in skills to alter behaviour. Parrish (1986) states that education aims to improve medication compliance via the transmission of information concerning a disease and its treatment. This raises issues with the results obtained in the literature to date. The central problem is that it cannot be effectively stated whether the results were due to the education component, skills training or a combination of the both. Parrish (1986) concur with this assertion by stating that despite the plethora of literature regarding the combination of training techniques and incentives, there are relatively few studies which have examined the incremental contributions made by the various components of these packages. Therefore, in order to establish the relative contribution of the components it is suggested that future research concentrate on comparing both educational and skills training to establish their relative merits vis a vis asthma in general and medication compliance in particular.

1-3-9 RATIONALE FOR THE PRESENT STUDY

New Zealand has an unenviable record as the world leader regarding the prevalence of asthma and deaths due to this condition. Evidence of this is the increasing prescription of asthma medications and rising admissions to paediatric wards. This high morbidity expresses itself in increased visits to the doctor, hospitalizations and time off school. All of which may result in

increased family pressures, loss of education, reduced social interaction and increased cost to the family. A disturbing aspect is that the number of asthma deaths in New Zealand is unnecessarily high (Sears et al., 1985). Retrospective study of medical records has shown that, prior to death, many of the study population exhibited low levels of comprehension concerning the appropriate use of asthma medications (Sears et al., 1985).

Although asthma cannot be cured, the medical technology exists to control the condition. However, there is a discrepancy between the availability of medication, its therapeutic potential and actual efficacy (Rachelefsky, 1987; Van Asperen et al, 1986). The reality is that no matter how good the available medications for controlling asthma are, it is generally assumed that they cannot be effective unless administered as prescribed. Research shows that compliance with prescribed regimens is a recurring problem in chronic illness (Deaton, 1985; Radius et al, 1978). The most reliable estimates of compliance rates range from 30-50% (Radius et al, 1978; Deaton, 1985). Reasons for non-compliance in asthma are varied; encompassing forgetfulness, administration errors, lack of comprehension and ignorance. Further, Spykerboer, Donnelly & Thong (1986) state that the lack of optimal control of asthma is in a large part due to the lack of knowledge by the sufferer and significant others.

A variety of behavioural methods have been employed to increase compliance, including self-monitoring, reinforcement procedures (Melamed & Siegal, 1980) and reminder behaviours (Rapoff, 1986). Such methods have met with success within studies and in individual cases; however with increasing numbers of people suffering from asthma it has been seen as crucial to disseminate solutions as widely as possible. The result has been an emphasis on developing packaged education programmes for delivery to groups of sufferers.

It is suggested that the lack of knowledge, whether due to miscomprehension or inadequate instruction, is incompatible with efficacious treatment. To overcome this, education employing social learning theory techniques, has come to be one of the main interventions both in New Zealand and overseas. The focus has been on providing knowledge, facts and solutions to deal with the problems associated with complying; emphasizing the self-care and responsibility aspects. Positive results have been reported detailing associated decreases in morbidity (Hilton, 1986; Taggart et al, 1987; Modell et al, 1983), visits to the doctor (Mitchell, Fergusson & Norwood, 1986; Hilton, 1986), increases in asthma related knowledge (Van Asperen et al., 1986; Hilton, 1986; Goldstein, Green & Parker, 1983) and increases in medication compliance rates. The stated aim of these programmes is to change

the attitudes and beliefs concerning asthma in order to promote self-management.

However, the major problem with the literature to date is that there have been no clear indications as to what exactly constitutes education. Indeed researchers e.g. Hindi-Alexander (1985), state that asthma education concerns the presentation of information and skills to better control asthma. Thus, although positive results have been obtained with education programmes these programmes are, in fact, a mixture of education information and behavioural / compliance skills training. The findings to date do not state clearly whether the results obtained are due to the education component, skills training or a combination of both.

To fully gain an understanding of the value of education and skills training on an area such as medication compliance, it is necessary to establish the relative contributions of each component. The end-result would be a clearer understanding of the best means to control this serious problem. This in turn may lead to improved targeting of skills and limited resources.

Paediatric asthma is an area where non-compliance is of special concern. For the most part it is the parents who will organize, oversee and administer the prescribed medications to their children. It is also to parents that education programmes have been directed, for this reason parents were targeted for intervention within the present study. By monitoring their compliance behaviours, pre- and post-intervention, it will be possible to establish the relative effects of each intervention package employed. The current study examines the relative effects of education information, skills training concerning medication compliance plus a combination of these. The effects are compared, over a number of variables, with a matched self-monitoring control group.

The following section describes in detail the present study. It is hoped that by offering distinct education, compliance and combination packages and then comparing changes with a control group over time that the relative effects of each component concerning medication compliance will be established. No specific hypothesis has been formulated regarding the expected outcome as the aim of the study is to establish the relative effects of each component.

METHOD

2-1 SUBJECTS

Participants for this study were enlisted from families with children attending the Paediatric Outpatients asthma clinic at the Christchurch Public Hospital. To be eligible, the children must have received a diagnosis of moderate-severe asthma (Phelan, Landau & Olinsky, 1982) by a staff physician at Christchurch Public Hospital. Potential subjects were approached by the primary investigator during clinic sessions; these are held on the first two Mondays of each month.

Subjects were required to have a child on a prescribed regimen involving one or more inhaled medications. This required a set prescription for the number of "puffs" per administration and the number of administrations per day. Use of inhalers on an "as needed" basis (i.e. only during attacks) was unacceptable. Experience with the use of inhalers varied from initial demonstration by the family doctor to instruction from staff at the clinic. In addition, all subjects were required to have in their home and be familiar with the Wright Mini Peak-Flow meter (Wright, 1978). If the family did not have a peak-flow meter the Paediatric Department supplied one free of charge. Novice users were given four days familiarization period before recordings of readings commenced. In all cases the primary investigator checked knowledge of and practical use of the peak-flow meter prior to commencement of the study.

The final subjects were then assigned to the three experimental and one matched self-monitoring control groups. The composition of each group was obtained by quasi-random assignment.

2-2 EXPERIMENTERS AND PERSONNEL

The primary investigator was a 29 year old male postgraduate psychology student at the University of Canterbury. The primary investigator was responsible for all facets of design in the current study, selection of topics to be covered and the information presented.

The associate investigator, Mrs A. Wilkie, is currently employed in a half time capacity as asthma educator for the Canterbury Hospital Board. In

addition she is on the committee of the New Zealand Asthma Foundation and also the Canterbury Asthma Society.

2-3 SETTING

Subjects completed the recording of all information for the questionnaires and dependent variables within their own homes i.e. the natural medication administration environment. The teaching sessions were conducted at two separate locations; it was not possible to book one location for all times needed. As far as was possible both locations were set up to be identical. The rooms were arranged to accommodate a small group of six subjects and one educator. Equipment available in both rooms was identical, being a blackboard for the writing of information and a stand for the display of posters. Each room was closed off from outside noise and interference; lighting and acoustics were similar in both situations.

Both the Education and Compliance groups attended their classes at Christchurch Public Hospital, in the seminar room of the Paediatric department. Sessions for the Education group were scheduled for four consecutive Monday mornings with each session lasting for one hour. The Compliance group's sessions were scheduled for the same four consecutive Mondays however these sessions ran for one hour in the evening. The final group (a combination of education and compliance training) attended sessions at a teaching room within the Psychology Department at the University of Canterbury. The room was chosen specifically for its closeness in size and layout to that used in the hospital setting. Four sessions were held on consecutive Friday afternoons, each lasting one hour.

2-4 DEPENDENT VARIABLES

2-4-1 Medication

As the central issue in compliance is the correct administration of medicines, a measure of bronchodilator usage was chosen as the main dependent variable. Insufficient subjects were prescribed pills to allow this measure to be chosen as a dependent variable. The children's own metered-dose inhalers were used throughout the study. These were of two types - the dry powder inhaler and aerosol pressurized inhaler. All inhalers were of the types commonly available on prescription within New Zealand. Each subject was required to record (on sheets provided) the exact amount of medication

administered to the child e.g. two puffs and the time of day this occurred at. Thus the record sheet (see Appendix 4) detailed the exact number of puffs inhaled, the time of day this occurred at and the number of administration. Smith, Seale & Shaw (1984) state that the incidence of false reporting by mothers is low. They found a high correlation between the mothers' reported administration and actual levels as determined by bioassay. Each mother was instructed that if the medicine was given at a different time to normal administration time they were to place the recording alongside the time it was actually administered, not when they would normally have administered it. If the particular dose was forgotten or not administered then mothers were asked to either leave the relevant square blank or else place a cross through it. Correct administration or compliance was deemed to be when all inhalers given on each particular day were identical to the instructions given by the relevant physician. The formula used to calculate the percentage of compliance was:

$$\frac{\text{No. of puffs at each administration} \times \text{No of administrations per day}}{\text{No. of puffs prescribed} \times \text{No. of times per day prescribed}} \times \frac{100}{1}$$

Any instance where the number of puffs varied from that prescribed or the number of administrations per day differed from the regimen was treated as non-compliance.

The recording of medications administered was to be carried out in the subject's own home as this is the environment that administration occurs in. Inhaler medications were chosen as the major dependent variable as the vast majority of the potential subject pool are on prescribed inhalers. The rationale for choosing self-report measures by the subjects was that they are primarily responsible for administration and most medicine taking occurs within the home. Therefore, the parent is ideally suited to record actual administration.

2-4-2 Peak Flow Recorder

The device employed to measure the child's respiratory flow rate is the Wright Mini-Peak Flow Meter (Wright, 1978). The device consists of a mouth piece affixed to a chamber, which has scaled numbers along the side. By blowing into the mouthpiece the forced expiration moves a flange against a spring and this pushes a small indicator along the scale. The resulting number indicates the amount of air expired in the initial 0.1 seconds by the child. By obtaining the recording it is possible to check whether the child's pulmonary function is within the desired or typical range for a child of that height and age. Further, this acts as an objective measure concerning whether or not the child has complied with medication.

Subjects were required to have their child blow into the peak flow meter twice daily, once in the morning and once again in the afternoon. Both of these times were to be before the administration of asthma medications. The rationale for this was to derive a measure of lung function unaffected by recent medications and thus obtain an indication of medication compliance. In order to derive an accurate reading the subject was requested to record only the "best of three" blows.

The recording sheet for peak-flow data (see Appendix 5) was adopted from the form employed by the Christchurch Public Hospital. The sheet is simply laid out in a grid pattern so that the subject merely had to place a dot on the correct grid to represent the particular score obtained. To ascertain whether the peak-flow was within the appropriate range each recorded point was compared to the expected norm for a child of that particular height and age. These figures are derived from New Zealand norms research (St. George, Reid, Grimmond & Morton, 1982). The formula used to ascertain whether the performance was adequate was:

$$\frac{\text{actual performance score}}{\text{standard score}}$$

As the subjects recorded two readings per day for all four phases of the study, it was decided that the mean value of all recordings, for each subject in each phase, be used.

The rationale for choosing the self-report method was as described earlier in this section.

2-4-3 Knowledge Questionnaire

This questionnaire is designed for parents to fill out concerning their knowledge of asthma. The questionnaire consists of four parts :

- (a). multi-choice items addressing treatment and triggers
- (b). a rating scale (never-always) to indicate the frequency of asthma related behaviours exhibited by the child
- (c). a series of true / false statements concerning how the parent believes the child feels about his/her asthma
- (d). a rating scale ranging from never to always, regarding parent's impressions on the frequency of given situations / behaviours.

The questionnaire was developed as part of the Airpower education programme (Airpower, 1984) (see Appendix 6). It was employed as a variable to be administered pre- and post- intervention.

2-4-4 Health Locus of Control Scale

This questionnaire was developed by Lau & Ware (1981) to assess the degree to which individuals believe they have control over their health. It consists of 21 statements which are rated on a seven point scale ranging from 1= strongly agree to 7= strongly disagree (see Appendix 7). These statements are divided into four subscales for which an average score is determined for both the individual and the group. The subscales are labeled as follows: Self Control over Health, Provider control over health, Chance Health Outcome and General Health Threat. By obtaining scores for each of the groups, both pre and post test, on all four subscales it was hoped that an indication would be gained concerning whether a particular intervention enhanced the change in beliefs towards the internal locus of control associated with self- management practices.

2-4-5 Morbidity Scale

This scale was included as part of a general family questionnaire used to gather demographic data (see Appendix 8). It was developed as part of the Airpower education programme (Airpower, 1984). It requires the parent to provide details of days off school, days in bed, visits to the doctor, accident and emergency visits and hospitalization due to asthma. This scale was employed to if intervention had any effects on the level of morbidity within each group.

2-4-6 Participant Evaluation

A questionnaire was developed by the primary investigator specifically to gauge the perceived changes for the subjects who participated in the present study (see Appendix 9). The aim was to give subjects an opportunity to evaluate the programme and summarize the ways in which they benefited, or not, from participation. The form was in two sections, Part A consisted of eight statements regarding possible changes which may have occurred during participation. Subjects were asked to rate their feelings about each statement, ranging from -3 (disagree strongly) through to +3 (agree strongly). Part B consisted of a series of five open- ended statements concerning impressions of the content and efficacy of the classes held.

2-5 DESIGN

The design employed in the study was a group comparison treatment with repeated measures (Kazdin & Wilson, 1978). The study incorporated four

different groups labeled as follows: Education, Compliance, Combination and Control. With six subjects in each group the final subject pool totaled twenty-four persons. Measures were taken over four phases : Baseline, Intervention, Six week probe and Twelve week probe. These measures were compared between groups to test for any significant changes over time. The aim was to compare specific education packages and their effect on medication compliance against performance by a matched self-monitoring control group.

2-6 PROCEDURE

Upon obtaining informed consent (see Appendix 10), the twenty four subjects were each assigned to one of four groups (N=6) : three treatment and one matched self-monitoring control. This assignment was on a quasi-random basis; conflict between subjects' prior commitments and session times precluded pure randomization. Notification of session times and dates of the programme were then forwarded to all subjects via mail. Prior to the first session all subjects were requested to record baseline data lasting three weeks. The primary investigator visited each subject to explain exactly what was required and how to fill in the data sheets. This data comprised a questionnaire on general history and demographics (including the asthma morbidity scale), the Health Locus of Control scale, asthma knowledge questionnaire and daily recordings of medications administered and peak-flow readings. In conjunction with the contact via mail, the primary investigator contacted each subject personally to outline the procedures involved in filling out the various questionnaires and recording sheets.

The second phase involved active intervention, by way of four organized sessions on four consecutive weeks, for the three treatment groups. The self-monitoring control group received no intervention / education of any kind. All subjects including the self-monitoring control group completed daily recordings of medications administered and peak-flow readings throughout the four week phase. In addition, all subjects completed an asthma knowledge questionnaire and a Health Locus of Control scale at their leisure. At the beginning of each session, all subjects in the treatment groups were requested to listen attentively and feel free to ask questions. It was explained that there was no need to take notes as handouts would be distributed to take home.

Presented below is an overview of content for each of the four sessions attended by members of the three treatment groups. A complete reproduction of each session's content may be found in Appendices 1, 2 and 3.

2-6-1 Compliance Training

Session 1 - The focus of this session was comprehension concerning asthma related medications. It is felt that by increasing understanding of the major medications then obstacles to compliance may be overcome. To facilitate this, an overview of basic physiology was presented along with a description of what occurs during an asthma attack. This was aimed at clarifying misunderstanding concerning how we breathe and the effect of asthma. As the central means of managing asthma is pharmacotherapy, information was presented regarding common New Zealand medications. These medications were presented in groups according to their roles; relievers, preventers and steroid medications. Within each section information was presented concerning the form of each medication, time it took to work, its safety / side-effects and usual dosage. The final information consisted of the correct administration of medications, along with a rationale for its importance.

Session 2 - This session attempted to deal with the problem of communicating with doctors; the aim was to promote an active partnership in therapy. It was suggested that this could be achieved by identifying and resolving problems concerning doctors. Once the problems associated with communication were identified, possible solutions were presented to the group. Subject's views of doctors were solicited, with the view to discussing stereotypes and their possible negative effects which may colour relationships with doctors. This theme was expanded in ideas for interaction with the doctor and establishing lines of communication. A concrete solution offered to overcome the problem of forgetfulness was the idea of writing down information both for giving and receiving. The session finished with a group discussion on patient's rights and responsibilities when dealing with doctors.

Session 3 - The content contained information about comprehension difficulties and also included errors in administration of medication and ways to overcome these. The first part of the session looked at understanding prescription labels in order to overcome difficulties with comprehension of administration instructions. Information was presented explaining the intention of common instructions which accompany asthma medications. The second half of the session dealt with the problem of remembering to take medications appropriately. Subjects were introduced to the theory of memory and learning, problems associated with this and then presented with a method to overcome this - a referral chart. This was followed by a summary of rationale for using a referral chart and presentation of a method to learn material better - PQ₄R (Anderson, 1984).

Session 4 - This final session continued with skills to overcome the problem of forgetting to administer medications. The content dealt with problems of administering medication within the family setting, the use of association of medications with a routine activity, tailoring medications to fit family activities and use of an asthma diary. Theory concerning the association of activities with frequent occurrences was presented along with practical examples. Rationale for tailoring the medication regimen to suit the family was presented in order to decrease activities competing for attention span. Finally, the idea of an asthma diary was presented along with copies for use at home. Discussion promoted the benefits of using the diary to enhance communication and therefore relationships with their doctors.

2-6-2 Education Group

All the following sessions are based on the "Open Airways" (1984) programme.

Session 1 - The session began with a group discussion concerning feelings about asthma. This was to allow the subjects to express their concerns and ideas to each other, engendering the idea that they were not alone with this problem. Each subject was asked to contribute problems and / or fears for the group to discuss and consider. The next part involved presentation of basic information concerning the condition. A description of asthma and its effects was offered, followed by a discussion on the early signs, triggers and role of emotions. Throughout this session a number of posters were displayed with themes relevant to the topics under discussion. The session ended with a demonstration of deep breathing to help promote relaxation during an attack.

Session 2 - The theme of this session was offering ways for parents to help their children to stay active and healthy despite asthma. The educator promoted the idea that regular exercise is important although subjects may have concerns about this exercise. Parents were assured that such concerns were natural and then the group discussed possible solutions to problems mentioned. This resulted in the presentation of a set of guidelines to help the children safely increase the amount of exercise they get. The second half of the session dealt with another relaxation technique plus the rationale for using relaxation during an attack. The aim was to practice tensing muscles and then relaxing, with the goal of subjects experiencing the worth of relaxation.

Session 3 - Subjects were taught ways to manage an attack at home and when to decide to seek medical attention. The aim was to increase subject's confidence in their ability to manage an attack in conjunction with medications. A series of non-medical skills were presented such as being

aware of "early warning signs" regarding attacks, the importance of fluids and the use of relaxation. Following this, a list of six signs regarding when to call a doctor was taught. It was emphasized that these skills can help the subject to deal more effectively with attacks. The final part emphasized the need for both parent and child to work as a team during an attack. To this end a demonstration of massage techniques was given for use during future attacks.

Session 4 - This final session was concerned with the control of asthma triggers commonly found within the home environment. The purpose was to show another way in which subjects can be successful in controlling asthma and also offer solutions for reducing triggers within the home. A group discussion focussed on common triggers of asthma attacks which are found in most homes. Common triggers such as pollens, cigarette smoke, pets and weather were discussed and sensible solutions offered. The session ended with a summary of the four sessions and subjects comments; with the chance to review any material still causing concern.

2-6-3 Combination Group

The content of these four sessions is derived from a combination of material presented thus far. The first two sessions were conducted by the primary investigator and covered material presented to the Compliance group. The final two sessions, involving material presented to the Education group, were conducted by the associate investigator.

Session 1 - Material presented in this session was of the same content and format as that presented to the Compliance group. However, due to time limitations the amount of material presented was restricted; any material not covered was presented in the form of handouts. Material consisted of basic physiology, function and types of medications and the correct use of inhalers plus a shortened discussion concerning communication with doctors. Subjects were each given a handout detailing intended meanings for medication instructions.

Session 2 - This was a combination of sessions three and four given to the Compliance group. The aim was to deal with errors related to administration problems with medications, particularly problems due to forgetting. The first half of the session dealt with the theory of memory and learning plus associated problems. To reinforce this, subjects were given a handout detailing the rationale for using a referral chart plus a referral chart for home use. The second half dealt with associating medication administration with routine activities and tailoring the medication regimen to suit the family's activities.

The session ended with a summary of the benefits of using an asthma diary and each subject was given copies for personal use.

Session 3 - This material was presented by the associate investigator, being an amalgamation of material used in sessions one and two with the Education group. The session began with a discussion on subject's feelings about asthma, especially any fears they might have. Immediately after this was the presentation of information on asthma such as basic signs and triggers. Once subjects were comfortable with this, material was presented relating to exercise and general health. Posters and handouts used were identical to those within the Education group's sessions.

Session 4 - A combination of material from sessions three and four of the Education group was presented. Content included a variety of relaxation techniques to use during asthma attacks. In addition, details concerning signs and symptoms which indicate medical assistance is needed were presented. The final information dealt with the home environment and common triggers found there in. Subjects were encouraged to describe triggers they had encountered plus means of overcoming them. Emphasis was placed upon the subject's ability to control aspects of life and the environment which affect their child's asthma.

2-6-4 Six Week Maintenance Probe

This phase was scheduled for six weeks after completion of intervention, materials were posted out to subjects from all four conditions. They each received daily recording sheets for peak-flow readings and medication administration, an asthma knowledge questionnaire plus a Health Locus of Control scale. A covering letter requested that subjects record dependent variables daily for one week as well as complete the questionnaires. A self-addressed envelope was enclosed to ensure prompt return of the data. If materials were not returned within one week following completion of recordings a reminder phone-call was made to the subject concerned.

2-6-5 Twelve Week Maintenance Probe

This phase was scheduled for twelve weeks following completion of intervention phase. Materials were posted to twenty three of the original twenty four subjects; the 24th subject withdrew due to personal reasons. The remaining twenty-three subjects received daily recording sheets for the dependent variables (peak-flow readings and medication administration records). In addition each subject also received an asthma questionnaire, a

Health Locus of Control scale plus a follow-up questionnaire containing a morbidity scale.

The final item included, was a questionnaire developed for the study designed to gauge subjects' impressions regarding the benefit or otherwise of the programme. Instructions for this final phase were to complete daily recordings of the dependent variable over a period of one week, complete the questionnaires and return all data in the envelope provided. Any recordings not received one week following completion of recordings were followed up by a phone reminder.

Following completion of data analysis and writing of the report all twenty-four subjects were contacted by the primary investigator. The letter expressed gratitude for the subject's participation and set out the major findings of the study in lay terms.

RESULTS

3-1 SUBJECTS

The subject population comprised twenty-four mothers aged between 27 and 42 years with a mean age of 34 years. Each was the mother of an asthmatic child (either sex) aged between four and nine years. Subjects described their ethnic group as Caucasian (21), Maori (1), Polynesian (1), Asian (1) and stated their educational standard as ranging from "less than fifth form" to having "some university education" (not graduate). The mean level of education was having "completed either sixth or seventh form". Socio-economic status was assessed using the Elley & Irving (1972) scale based on the 1966 New Zealand census. The range, for all subjects, was Level 1 - Level 5 with a mean SES rating of 3.

Initial approaches produced eighteen agreements to participate from twenty-six enquiries. Reasons cited for non-participation included lack of time and existing confidence in ability to cope with asthma. The remaining six subjects were obtained via telephone contact; names and eligibility being confirmed through hospital files. During telephone enlistment eight parents declined to participate, the major reason given was confidence in their present abilities and knowledge.

In terms of the study, 23 of the 24 mothers completed all aspects of data recording through to the twelve week follow-up. The one exception completed all recordings up to and including the six week follow-up. This mother was unable to complete final data recordings at twelve weeks due to personal difficulties. Relevant data for the twelve week follow-up were pro-rated for this individual, on the basis of her previous recording history. Attendance at sessions, run throughout the programme, were : 10 subjects attended all four sessions as required, six attended three out of the possible four and two attended two sessions. The remaining six subjects constituted the matched self-monitoring control group, who received no intervention. The reasons given for non-attendance were conflicting prior-scheduled arrangements, children sick and one mother forgot to attend one session. All sessions which were missed were fully covered by way of detailed handouts. Thus, all subjects in each group received the basic information covered in all four sessions.

Analysis of results involved a one way Analysis of Variance to determine treatment effects and any subsequent maintenance effects. Graphical presentation of any significant main or interaction effects will take the form of line / bar graphs (as appropriate) for ease of interpretation. ANOVA summary tables will be presented for all variables to clarify findings.

3-2 TREATMENT EFFECTS

Throughout the following section, the labels "group 1", "group 2", "group 3" and "group 4" will refer to Education, Combination, Compliance and Control groups respectively.

3-2-1 Medication Compliance (Inhalers)

All groups demonstrated a significant increase in their mean use of inhalers, from recordings taken at baseline (90%, 92%, 88%, 89% for groups 1 to 4 respectively) to those at intervention (97%, 96%, 92%, 94% for groups 1 to 4 respectively). ($F(1,20) = 6.113$, $p < 0.05$), (see Table 3).

Table 3: ANOVA Summary Table for Mean % of Prescribed Doses

Source of Variation	df	Sum of Squares	Mean Square	F	p	Epsilon Correction
G	3	112.694	37.565	.247	.8626	
Error	20	3044.165	152.208			
I	1	276.144	276.144	6.113	.0225	
GI	3	8.606	2.869	.064	.9785	
Error	20	903.409	45.170			1.00

Table Legend

G = group I = medication GI = group by medication interaction

Figure. 1. shows the change in medication usage by all groups between baseline and intervention phases.

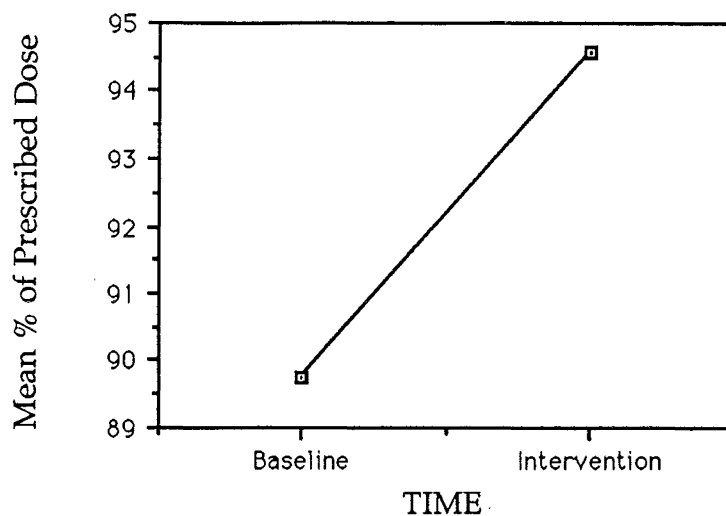


Figure 1. Mean inhaler usage for all groups.

3-2-2 Child's Peak-Flow Readings

No change was evident; the four groups did not differ significantly in peak-flow readings between baseline (1.27, 1.33, 1.42, 1.34) and intervention phases (1.37, 1.31, 1.45, 1.49), where 1 = a performance as expected by normative data (St. George et al, 1982). (see Table 4)

Table 4: ANOVA Summary Table for Child's Peak-Flow Recordings

Source of Variation	df	Sum of Squares	Mean Square	F	p	Epsilon Correction
G	3	.138	.046	.220	.8814	
Error	20	4.187	.209			
P	1	.051	.051	2.725	.1144	
GP	3	.048	.016	.854	.4808	
Error	20	.377	.019			1.00

Table Legend

G = group P = peak flow GP = group by peak flow interaction

3-2-3 Morbidity Measures

(a). Doctor's Visits

All groups displayed a significant decrease in visits to the general practitioner for asthma care. The recording period was for the three months prior to baseline (1.50, 1.33, 1.17, 1.00) compared with the three months between

baseline and twelve week probe (0.17, 0.83, 0.33, 0.50). ($F(1,20) = 5.085$, $p < 0.05$) (see Table 5).

Table 5: ANOVA Summary Table for Doctor's Visits

Source of Variation	df	Sum of Squares	Mean Square	F	p	Epsilon Correction
G	3	.896	.299	.209	.8890	
Error	20	28.583	1.429			
D	1	7.521	7.521	5.085	.0355	
GD	3	1.396	.465	.315	.8147	
Error	20	29.583	1.479			1.00

Table Legend

G = group D = Doctors' visits GD = group by visit interaction

Figure 2 represents the decrease in doctors visits for all groups between this time period.

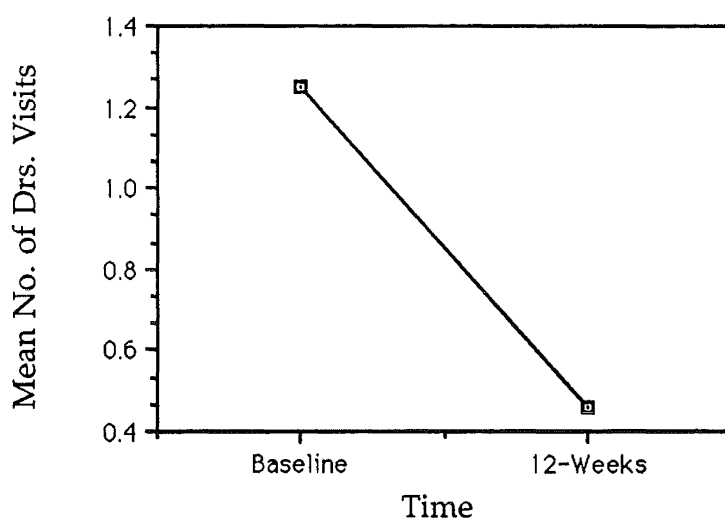


Figure 2. Doctors Visits

(b) Hospitalization

The groups displayed a significant decrease in the number of hospitalizations. The recording period was for the three months prior to baseline (0.16, 0.00, 0.33, 0.50) compared with the three months between baseline and twelve week probe (0.00, 0.00, 0.16, 0.00). ($F(1,20) = 4.032$, $p < 0.05$). (see Table 6).

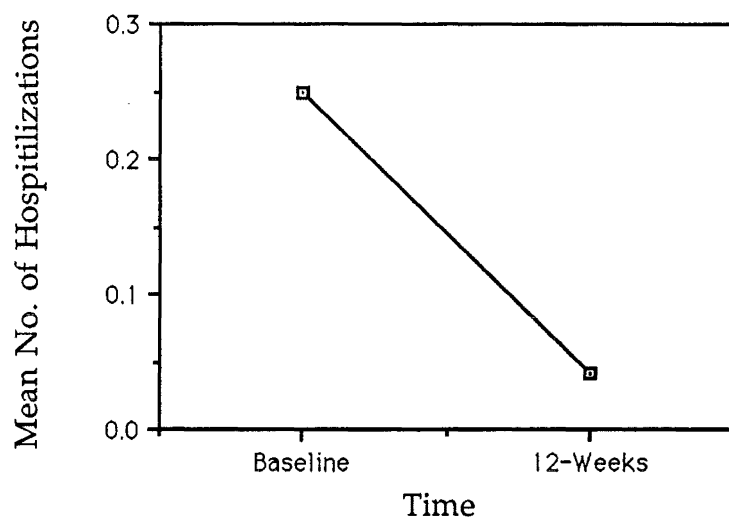
Table 6: ANOVA Summary Table for Number of Hospitalizations

Source of Variation	df	Sum of Squares	Mean Square	F	p	Epsilon Correction
G	3	.563	.188	.957	.4320	
Error	20	3.917	.196			
H	1	.521	.521	4.032	.0583	
GH	3	.396	.132	1.022	.4041	
Error	20	2.583	.129			1.00

Table Legend

G = group H = hospitalizations GH = group by hospitalizations interaction

This is represented in figure 3.

Figure 3. Hospitalizations

(c). Number of Asthma Attacks

The Analysis of Variance revealed that the groups recorded significantly different numbers of attacks. The recording period was for the three months prior to baseline (2.25, 1.75, 9.25, 1.50) compared with the three months between baseline and twelve week probe (1.25, 1.00, 8.75, 1.25). ($F(13,20) = 3.488$, $p, 0.05$), (see Table 7).

Table 7: ANOVA Summary Table for Number of Asthma Attacks

Source of Variation	df	Sum of Squares	Mean Square	F	p	Epsilon Correction
G	3	512.391	170.797	3.488	.0349	
Error	20	979.313	48.966			
A	1	5.672	5.672	.116	.7374	
GA	3	1.641	.547	.011	.9983	
Error	20	981.563	49.078			1.00

Table Legend

G = group A = asthma attacks GA = group by asthma attacks interaction

This is illustrated in Figure 4.

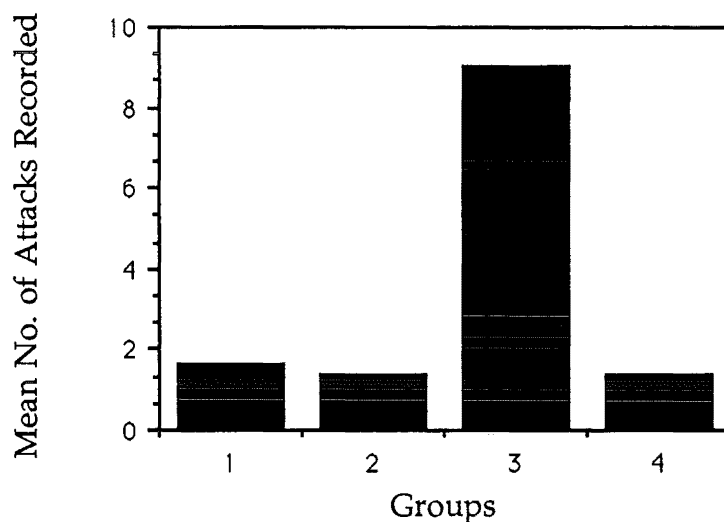


Figure 4. Number of Asthma Attacks

Figure Legend Group 1 = Education;
Group 2 = Combination;
Group 3 = Compliance;
Group 4 = Control.

The aposteriori t-test showed the compliance group to have significantly more asthma attacks than all other groups ($p < 0.03$), with no difference between controls, education and the combination groups.

(d) Days in Bed Due to Asthma

No change was evident. The four groups did not differ significantly on days in bed due to asthma between the three months prior to baseline and the three months between baseline and twelve week probe (see Table 8).

Table 8: ANOVA Summary Table for Days in Bed

Source of Variation	df	Sum of Squares	Mean Square	F	p	Epsilon Correction
G	3	11.563	3.854	1.649	.2100	
Error	20	46.750	2.338			
B	1	3.521	3.521	2.265	.1479	
GB	3	6.896	2.299	1.479	.2505	
Error	20	31.083	1.554			1.00

Table Legend

G = group B = days in bed GB = group by days in bed interaction

The remaining variables were measured over three of the four experimental phases (Baseline, Six weeks after intervention and Twelve weeks after intervention).

3-2-4 Parental Asthma Knowledge

No treatment effect was evident; the four groups did not differ significantly in levels of asthma knowledge between baseline (85, 75, 77, 67) and the six-week probe (78, 80, 81, 77). (see Table 9).

Table 9: ANOVA Summary Table for Parental Knowledge Scores

Source of Variation	df	Sum of Squares	Mean Square	F	p	Epsilon Correction
G	3	539.750	179.917	1.464	.2545	
Error	20	2458.167	122.908			
K	1	126.750	126.750	1.558	.2264	
GK	3	506.083	168.694	2.073	.1359	
Error	20	1627.167	81.358			1.00

Table Legend

G = group K = knowledge scores GK = group by knowledge interaction

3-2-5 Parental Ratings of Asthma's Impact on the Family

Both the Education and the Combination groups show significant decreases in their ratings of the impact of asthma on the family between baseline (78 and 80 for Education and Combination respectively) and the six week probe following intervention (71 and 76). ($F(3,20) = 2.953$, $p < 0.05$), (see Table 10).

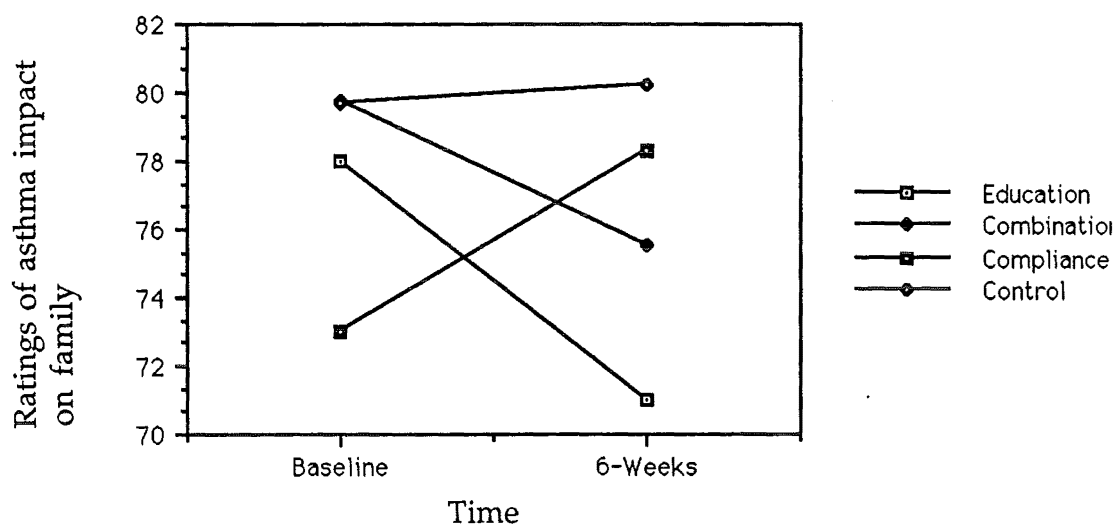
Table 10: ANOVA Summary Table for Parental Ratings of Asthma Impact

Source of Variation	df	Sum of Squares	Mean Square	F	p	Epsilon Correction
G	3	203.563	67.854	.345	.7932	
Error	20	3935.750	196.788			
M	1	22.688	22.688	.754	.3956	
GM	3	266.729	88.910	2.953	.0573	
Error	20	602.083	30.104			1.00

Table Legend

G = group M = asthma impact GM = group by asthma impact interaction

Thus they perceive the effects of asthma to be less at six weeks following intervention. The Control group remained stable in their perceptions (80 both at baseline and following intervention) whilst the Compliance group perceived the impact to increase between baseline (73) and six weeks following intervention (78). This interaction effect is illustrated in Figure 5.

**Figure 5.** Parental ratings of Asthma Impact on the Family3-2-6 Health Locus of Control Scale

(a). Self-Control over Health subscale

No change was evident. The four groups did not differ significantly in their beliefs in self-control over health between baseline (5, 4, 5, 4) and six weeks following intervention (4, 4, 4, 4). (see Table 11).

Table 11: ANOVA Summary Table for Self Control Subscale

Source of Variation	df	Sum of Squares	Mean Square	F	p	Epsilon Correction
G	3	4.659	1.553	1.392	.2744	
Error	20	22.320	1.116			
S	1	.191	.191	1.011	.3267	
GS	3	.435	.145	.768	.5252	
Error	20	3.772	.189			1.00

Table Legend

G = group S = self control GS = group by self control interaction

(b). Provider Control over Health Subscale

No change was evident. The four groups did not differ significantly in their belief in Provider Control over Health, between baseline (5, 6, 6, 5) and six weeks following intervention (5, 6, 6, 6). (see Table 12).

Table 12: ANOVA Summary Table for Provider Control Subscale

Source of Variation	df	Sum of Squares	Mean Square	F	p	Epsilon Correction
G	3	2.846	.949	1.651	.2094	
Error	20	11.489	.574			
P	1	.037	.037	.146	.7066	
GP	3	.738	.246	.966	.4282	
Error	20	5.093	.255			1.00

Table Legend

G = group P = provider control GP = group by provider control interaction

(c). Chance Health Outcome Subscale

All groups significantly increased their beliefs in Chance Health Outcome between baseline recordings (3, 2, 2, 4) and six weeks following intervention (3, 3, 3, 4). ($F(1,20) = 6.399, p < 0.01$), (see Table 13).

Table 13: ANOVA Summary Table for Chance Health Outcome Subscale

Source of Variation	df	Sum of Squares	Mean Square	F	p	Epsilon Correction
G	3	14.376	4.792	3.607	.0313	
Error	20	26.569	1.328			
C	1	2.632	2.632	6.399	.0199	
GC	3	2.872	.957	2.328	.1053	
Error	20	8.227	.411			1.00

Table Legend

G = group C = chance health GC = group by chance health interaction

Thus all groups have increased their beliefs that asthma is uncontrollable. The increase in chance health belief by all groups is illustrated in Figure 6.

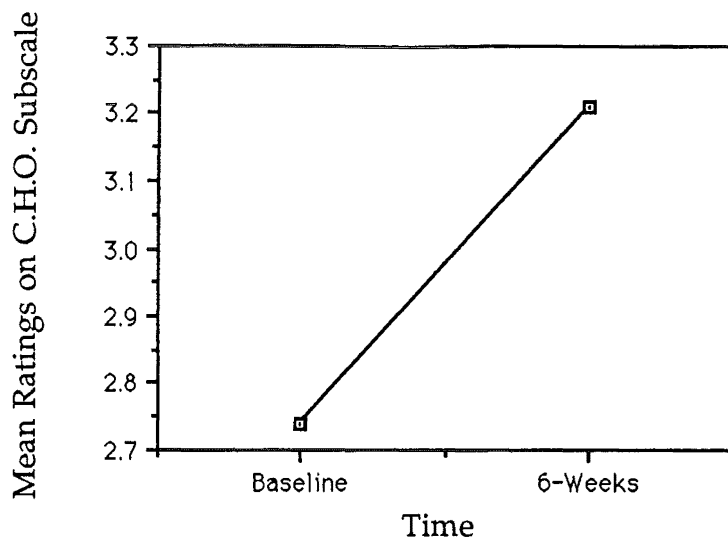


Figure 6. Chance Health Outcome Scale Ratings

The Control group scored higher on this scale than the three experimental groups between baseline and six weeks following intervention ($F(3,20) = 3.607$, $p < 0.05$), (see Table 13). This indicates a greater belief that asthma is determined by chance i.e. uncontrollable. The difference in beliefs was found to be significant when compared to those of the Combination group and Education group ($p < 0.05$, aposteriori t-test) and the Compliance group ($p < 0.01$, aposteriori t-test). This finding is illustrated in Figure 7.

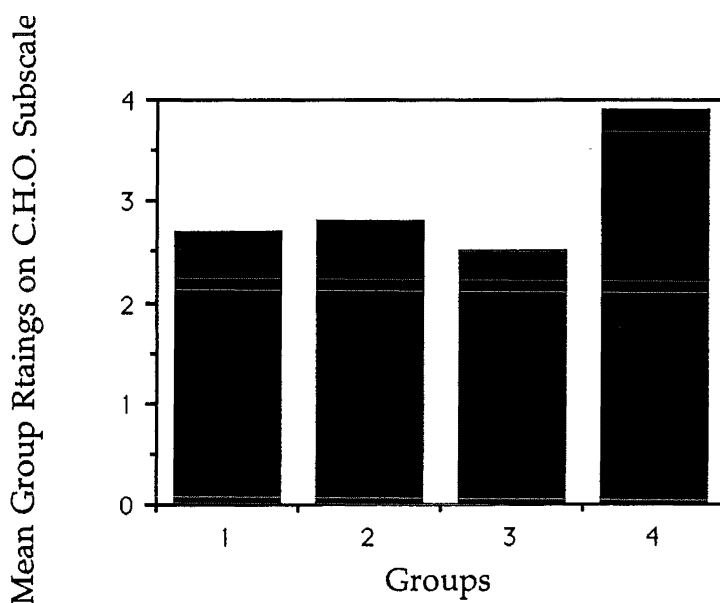


Figure 7. Chance Health Outcome Belief

Figure Legend Group 1 = Education;
Group 2 = Combination;
Group 3 = Compliance;
Group 4 = Control.

(d). General Health Threat Subscale

No change was evident. The four groups did not differ significantly in their beliefs in General Health Threat between baseline (5, 5, 5, 5) and six weeks following intervention (5, 5, 5, 5). (see Table 14).

Table 14: ANOVA Summary Table for General Health Threat Subscale

Source of Variation	df	Sum of Squares	Mean Square	F	p	Epsilon Correction
G	3	1.510	.503	.413	.7453	
Error	20	24.365	1.218			
G	1	.083	.083	.364	.5528	
GG	3	.781	.260	1.139	.3574	
Error	20	4.573	.229			1.00

Table Legend

G = group G = general threat GG = group by general threat interaction

3-3 MAINTENANCE EFFECTS

In order to determine any maintenance effects, a one way analysis of variance was carried out on the all variables where a significant treatment effect was evident.

3-3-1 Medication Compliance (Inhalers)

No decrease was found for mean percentage of prescribed medication compliance. The four groups did not differ significantly between intervention (96%, 96%, 92%, 94%), six week probe (95%, 96%, 95%, 93%) and twelve week probe (98%, 98%, 95%, 83%). (see Table 15).

Table 15: ANOVA Summary Table for Mean % of Prescribed Doses

Source of Variation	df	Sum of Squares	Mean Square	F	p	Epsilon Correction
G	3	69.770	23.257	.460	.7134	
Error	20	1011.375	50.569			
I	1	.312	.312	.005	.9443	
GI	3	34.154	11.385	.182	.9071	
Error	20	1248.032	62.402			1.00

Table Legend

G = group I = medication GI = group by medication interaction

The remaining variables were measured over three of the four experimental phases (Baseline, Six week probe and Twelve week probe). The following one way analysis of variance, carried out to determine maintenance effects, is between the six week probe following intervention and the twelve week probe.

3-3-2 Parental Ratings of Asthma Impact on the Family

Ratings of impact as given at the end of intervention did not change significantly between six and twelve weeks following intervention. The four groups did not differ significantly in their ratings of asthma's impact on the family between the six week probe (71, 76, 78, 80) and the twelve week probe (70, 72, 78, 81). (see Table 16).

Table 16: ANOVA Summary Table for Parental Ratings of Asthma Impact

Source of Variation	df	Sum of Squares	Mean Square	F	p	Epsilon Correction
G	3	736.396	245.465	1.079	.3803	
Error	20	4547.917	227.396			
M	1	22.688	22.688	.524	.4774	
GM	3	39.229	13.076	.302	.8235	
Error	20	865.583	43.279			1.00

Table Legend

G = group M = asthma impact GM = group by asthma impact interaction

3-3-3 Chance Health Outcome Subscale

The four groups did not change significantly with respect to ratings on the Chance Health Outcome Subscale between Intervention and the six week (3, 3, 3, 4) and the twelve week probe (4, 4, 3, 4). (see Table 17).

Table 17: ANOVA Summary Table for Chance Health Outcome Subscale

Source of Variation	df	Sum of Squares	Mean Square	F	p	Epsilon Correction
G	3	2.853	.951	.624	.6080	
Error	20	30.500	1.525			
C	1	.633	.633	2.358	.1403	
GC	3	1.037	.346	1.289	.3055	
Error	20	5.365	.268			1.00

Table Legend

G = group C = chance health GC = group by chance health interaction

3-3-4 Parental Ratings of the Study

This questionnaire was completed by all subjects following the final collection of data, twelve weeks following intervention. Responses to all questions were rated on a scale where: -3 = disagree strongly, +3 = agree strongly. Results represent the average rating for each group per question. Data is presented in Table 18.

Table 18: Mean Parental Ratings of Involvement in Study

Question	Educ.	Combo.	Compl.	Cntrl.
1. My attitudes and beliefs concerning asthma have changed over the last 3 months.	1.2	1.5	1.2	0.0
2. I feel more confident in handling my child's asthma after this study.	1.7	1.7	1.0	1.5
3. My knowledge concerning asthma has improved.	2.0	2.0	1.7	1.3
4. My ability to give medication correctly, as prescribed, has increased.	0.3	1.3	1.0	0.7
5. The health of my child during the last 3 months has improved.	1.0	1.8	0.3	1.5
6. Taking part in this study has been of benefit to myself and our family.	2.7	2.7	1.5	1.2
7. Such a programme would have been of benefit when my child was first diagnosed as asthmatic.	2.8	3.0	2.7	0.7

Table 18 (cont.)

8. I feel more able to discuss asthma, and clarify problems with my doctor, since taking part in this study.	1.7	2.2	1.0	1.0
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Overall it can be seen that all groups responded positively to the questions regarding participation in the present study. The minimum rating was 0 (neutral), and the highest was +3 (agree strongly). With respect to question #6, the ratings show a positive attitude towards the experience by all four groups, including the matched, self-monitoring control group. Question #7 shows that the three experimental groups, who all received some form of intervention, agreed strongly with the statement as worded, with scores of 2.8, 3.0 and 2.7, for groups 1, 2 and 3 respectively.

4 DISCUSSION

4-1 MEDICATION COMPLIANCE

The three experimental groups (Education, Compliance and Combination) plus the matched self-monitoring control group recorded a significant difference between baseline measurement and recordings at the intervention phase. The three experimental groups received specific intervention strategies and information aimed at increasing their rates of compliance. However, the matched self-monitoring control group received no active intervention aimed at increasing medication compliance. The requirement of this group was to complete daily recordings concerning either asthma or compliance training skills. Despite this lack of intervention the matched self monitoring control group recorded a significant increase in their rate of medication compliance. This increase was equivalent to that recorded by the three experimental groups following their completion of intervention programmes aimed at increasing compliance rates. The only component common to all four groups was the recording of daily medication data.

With research which relies on self recorded data there is always the possibility of demand characteristics influencing the veracity of subject's recordings. However, research to date has shown that subjects are able to record accurately their rates of compliance (Radius et al., 1978; Smith, Seale & Shaw, 1984; Shope, 1981). Indeed self recording is particularly useful for research such as the present, where the behaviour being recorded occurs naturally within the home environment. All subjects within the present study were informed of the need for honesty in recording compliance rates and specifically asked not to enhance recordings as the success of the study depended on honesty. In addition, peak flow recordings acted as an objective measure of compliance. Most children consistently recorded above the expected norms, which indicates consistent medication compliance. Thus, given the findings of research on reliability of self recording, plus this objective data it would seem safe to accept the data obtained in the present study as being reliable.

All four groups maintained this significant increase in medication compliance at a point twelve weeks following the end of the intervention phase of the study. Results of the present study demonstrate that interventions designed to increase medication compliance have no significant

effect over that obtained by way of self-monitoring. A simple recording task may well serve to cue administration responses and alter behaviour in line with the prescribed regimens. This finding of a self-monitoring effect, associated with recording procedures, is consistent with findings by Meichenbaum & Turk, (1987); Parrish, (1986); Varni & Babani, (1986); Lines, (1986); Weinstein & Cuskey, (1985); Whitman et al., (1985).

The effective change in the behaviour exhibited (medication compliance) may have been achieved as a result of the parent's increased awareness of their rate of medication administration. By recording daily the amounts of medication given to their child they would become aware of the level of administration and thus be in a better position to alter the behaviour in line with the desired goal i.e. they are reacting to the self-monitoring. A second possible reason for the effect of self-monitoring is that the act of recording the details, following completion of medication administration, may act as a form of immediate reinforcement. Parrish (1986) states that this immediate feedback from the act of recording will lead to an increase in parental compliance regarding the child's medication needs. The feedback will allow the parent to be aware that the child has received the medication as per physician's instructions and reinforce the parent for complying as suggested.

A further explanation for the effect of self-monitoring may relate to one of the central reasons for the high rates of non-compliance in study populations i.e. the fallibility of human memory (see compliance section). By recording daily the amount of medication administered and at what particular time, the act becomes a normal part of the parents' behaviour repertoire. In addition, the sight of a prominently placed recording sheet will act as a cue to exhibit the behaviour.

Two points should be addressed concerning self-monitoring and its effect on study populations :

(a). The effect tends to be short lived such that the reactive effect attenuates over time (Frederiksen & Simon, 1979). The present results show that the self-monitoring effects have equal power compared with intervention programmes at twelve weeks following the completion of intervention. However, given Frederiksen & Simon's (1979) caveat the effect beyond this point is undetermined by the present study.

(b). Frederiksen & Simon (1979) state that the effect of self-monitoring may be minimized within a population of non-motivated clients. As parents in the present study were motivated enough to volunteer to participate the effect of self monitoring may be heightened with this particular population. Therefore, to some extent , their reaction to the self monitoring may not be truly

representative of all parents of chronically ill children. Thus while considering the results of the increased compliance rates found within the present study it would be wise to be aware of the caveats raised by Frederiksen & Simon (1979).

Following on from this latter point, an area of concern is the presence of ceiling effects with motivated subjects. As is the case in the present study, subjects may present with baseline levels of compliance which are far higher than would be expected of a wider, more general population. This in turn limits the generalizability of findings, as there is the possibility that components of the programmes presented may have a different effect on a population with a lower baseline compliance rate. Therefore, the findings of the present study and conclusions drawn from them must be seen in the context of coming from a population who are already recording a high (89%) baseline rate of compliance.

The findings of the present study have certain implications concerning the development of programmes specifically designed to enhance medication compliance. The most poignant implication is that self monitoring appears to have an effect equivalent to that obtained by information presentation, skills training or a combination of both. Thus, in one sense self monitoring can be thought of as a treatment / intervention option in it's own right. The follow on from this is the effect on cost effectiveness of programmes implemented. If the sole aim of a given programme is to increase the compliance , then it would be less expensive to have clients fill out daily recording sheets than to hire a facilitator and arrange costly premises and materials. Associated with this are the benefits for the parents who would be involved in the programme, especially concerning the difficulties of juggling child-care and commitments, both personal and employment related. It should then be possible for the general practitioner or specialist to provide information during consultations and supply each individual with recording sheets to be filled out daily until the next consultation. In the initial stages (post diagnosis) this recording sheet may well act as a cue to administer medication , overcoming the memory problem associated with novel behaviours. Further, given the reliability of subject recordings, the physician would have at the next consultation, a fairly accurate indication of the parent's compliance rate. The above suggestion is of course contingent upon the parents' willingness to fill out such sheets. The ease of self monitoring at home would compare favourably with the problems associated with having to attend classes. However, this point is made only with respect to the aim of solely increasing compliance rates; attempting to concurrently increase parents' knowledge is another matter.

4-2 PEAK-FLOW RECORDINGS

Although no significant differences were found in either group or interaction effects for peak-flow recordings, an interesting point emerges if mean scores for all groups at baseline phase are compared to those for the intervention phase. The mean peak-flow recording for all groups at baseline was 1.3387 whilst the mean for intervention was 1.4042. A score of 1 represents a recorded measure equal to the expected norm for age and height of any given child (St. George et al., 1982). This increase was not statistically significant. What is indicated is that at baseline, the children (as a group) are performing better than expected for a child of that age and height per New Zealand norms (St. George et al., 1982). As has been said the recordings at intervention phase show no significant improvement but the children are still performing better than expected according to normative data.

For the present study the recordings of peak flow measurements were included as a dependent variable in order to act as a physiologically objective measure of medication compliance. Each recording was taken before medication was administered i.e. the furthest from previous administration. Thus, the measure of pulmonary function should be a good indicator of continual medication compliance. This is based on the not unreasonable assumption that if prescribed medication is complied with, then peak-flow recordings should be within the New Zealand norms for age and height as established by St George et al. (1982).

If this assumption is accepted, it follows logically that by increasing medication compliance then the individual child's pulmonary function should improve up to the established norm for his / her particular age and height. For example, if a parent only administers medication 20% of the time then the child's pulmonary function should be below par. By increasing compliance with medication, the recordings on the latter should increase as well.

It has already been noted that a significant increase in medication was achieved by all groups between baseline and intervention phases. However, there was not an associated significant increase in pulmonary function over the corresponding period. At baseline the mean compliance rate for all groups was 89.75% and the mean peak flow recording for all groups was 1.3387. Despite increasing medication compliance significantly (to 94.5%) post intervention, the pulmonary function did not increase significantly. The data obtained from the present sample shows that on average, the children in all four groups were performing to their better than expected optimal rate at baseline. This occurred even though they were being administered their

medication at the rate of 89%. Further, the data suggests that for the present sample population, a significant increase in medication compliance (over and above 89%) does not result in any significantly improved pulmonary function.

Results show that it is possible to increase compliance rates but the data does not show an associated increase in clinical outcome, if pulmonary function is to be accepted as an indicator of such. Consistent use in diagnostic procedures suggest a pulmonary function test may be employed as such. It would appear that an increase in medication compliance over and above a certain point does not result in improved clinical outcome. The question of just what is the degree of medication compliance necessary to achieve a satisfactory clinical outcome is not the domain of this thesis nor is it possible to ascertain from the data available. However, it is possible to say that increasing medication compliance, over and above the base rate of 89% for all groups, did not result in any improved clinical outcome to the children involved with respect to peak-flow measures.

4-3 MORBIDITY LEVELS

There was a significant reduction in morbidity levels for all four groups in the present study. This was measured by visits to the general practitioner for asthma related problems and hospitalizations for the same. The control group received no active intervention either in terms of information or compliance training skills, yet still recorded a significant decrease in morbidity. This significant reduction in morbidity levels may be partially attributed to the increased medication compliance and as such may be viewed as a self monitoring effect in itself. It is suggested that as a result of monitoring the administration of medications, parents become aware of their compliance rate and accordingly increase it. This may then result in fewer visits to the general practitioner and hospital. A second possible explanation may be found in relation to the parents' participation in the present study. All parents were aware that medication levels were being monitored, as were visits to the general practitioner. It is possible that parents may have been reluctant to visit the general practitioner unless absolutely necessary, for fear of being seen as not complying adequately i.e.. demand characteristics.

Of related interest is the finding that the overall number of asthma attacks (for all groups) did not decrease between baseline recordings and the three months following intervention. Thus, all groups remained constant with their experiences of attacks, despite increased compliance. The reason for this may well be found in the nature of asthma itself. Asthma is classed as a

variable and intermittent condition (Creer, 1982) which can be brought on by differing triggers for each attack e.g. physiological, allergic, psychological (Phelan, Landau & Olinsky, 1982). For these reasons it is possible that, despite complying with medication, asthma attacks may still be experienced at intermittent intervals. Of particular relevance however, is that although the number of attacks did not decrease, a significant reduction in doctor's visits and hospitalizations was recorded. This would suggest that although increasing medication compliance cannot reduce the overall number of attacks experienced, the increased medication compliance may be affecting the severity of these attacks. It appears that the attacks were managed within the home environment by the family and these attacks were not seen as serious enough to visit the doctor and involve hospital attendance.

An alternative explanation is that with the emphasis on administering medications, parents may have felt better able to cope with the attacks. This would consist of administering medications to control the attack rather than seeking assistance, unless essential. Such an explanation would be even more relevant to the three experimental groups. These groups all received information and / or skills, designed to deal with attacks and medication problems at home. Perhaps a more parsimonious explanation, which cannot be discounted, may be the recent increases in both physician related and prescription medication charges. The logical result from this would be an attempt to deal with the attacks within the home environment, unless it was truly an emergency situation. Whatever the reason for this decline in morbidity levels, it does appear to involve a more restrained and possibly increasingly judicious use of medical care facilities.

The significant finding with respect to asthma attacks experienced is that one group (Compliance) experienced a significantly different number of attacks than did Education, Combination and Control groups. There was no significant difference in the number of attacks between the remaining three groups for the period three months prior to baseline compared to the three month period between intervention and the twelve week follow up. A posteriori t-test showed that the Compliance group experienced significantly more attacks than the Education, Combination or Control groups for the period of recording. An explanation for this result can be found in the number of attacks recorded by all groups for the period of recording. One individual in the Compliance group was found to have a much higher number of attacks in each recording period than other members of his compliance group. Thus, the composition of the group is responsible for the significant difference. This finding is a direct artifact of the small N for groups such that one

disproportionate score is enough to account for a greater variance and affect the pattern of outcome results.

4-4 IMPACT ON THE FAMILY

Results show that following intervention the Education and Combination groups decreased significantly their ratings of the impact asthma has on the family. The common factor with both groups is the education material presented; neither the Compliance or Control groups received this material.

To understand why the education material may load so heavily on this variable it is helpful to look at the questionnaire used to rate impact (see Appendix 6). It can be seen that the content relates to the more intangible aspects of the disease i.e. the parent's feelings and concerns of how the child's asthma affects the family. This is as opposed to quantifiable aspects such as problems concerning medication. The focus of the education package was on parent's feelings about asthma, setting limits for the child and generally addressing things which caused the parents concern. Parents were free to discuss any general concerns about asthma and how it affected their families. A major emphasis of the sessions was on the idea of group support and allaying the fears experienced. Thus parents had a chance to realize that the problems associated with asthma were neither unsolvable nor unique to themselves. It is possible that by expressing these concerns within a safe group environment and discovering solutions the parents came to consider the impact of these intangibles to be less, post -intervention. This is borne out by the ratings for the education and combination groups.

In contrast, the Compliance group has recorded a significant increase in their ratings (post-intervention) of the impact of asthma. While this group were encouraged to express their feelings and concerns about asthma it was within the limits of medication related matters. The disease in general and family problems related to this were not dealt with. It is possible then that the coping skills provided to this group for medication related problems were of no assistance nor comfort concerning a parent's general feelings about asthma and the family. A possible enhancer for this line of reasoning is the scores recorded by the control group. At both recording periods the control group rated the impact of asthma on the family as being similar i.e. a constant perception of the impact. This is consistent with the explanation presented above, in that the control group received no intervention nor any chance to express their concerns as a parent of an asthmatic child. Accordingly, they may

well continue to perceive problems with the family and deal with them as they always have.

The implications of this finding are that parents do have a variety of concerns about asthma and its impact on the child and the whole family. To effectively decrease the impact of this concern it would appear that offering parents the chance to discuss problems / concerns with their peers in a safe environment is needed.

4-5 CHANCE HEALTH OUTCOME

The only significant finding on the subscales of the health locus of Control was for the Chance Health Outcome subscale. A high score on this subscale indicates that the subjects believe sickness and health are determined by luck whilst a mid-range score of 4 suggests that individuals still feel health is controllable.

The three experimental groups plus the control group increased their belief in the uncontrollability of asthma significantly between baseline and six weeks following intervention. However, post-intervention the mean rating for all groups was 3.2. This is below the midpoint of the scale suggesting that subjects still feel some control over health but all have significantly increased their ratings towards uncontrollability. The explanation for this may well be found within the variable, intermittent nature of the asthmatic condition itself. Asthma is manifested by attacks at varying intervals, even when compliance with prescribed regimens is high. If parents administer medications according to the physicians instructions yet the child still experiences attacks, their belief in the uncontrollability of the condition may well alter. This is especially poignant given that all subjects were recording levels of medication administered, peak flow readings, perceptions of asthma and the number of attacks experienced. Perhaps the parents became aware of the number of attacks their children had experienced between baseline and six weeks following intervention. Faced with recorded data concerning medications administered, it would be apparent that attacks are variable and thus parents may well adjust their beliefs on this dimension towards uncontrollability. Such a finding is in agreement with statements by Lau (1982), Lau (1988) and Lau & Ware (1981) that recent family experience with sickness should have an externalizing effect on beliefs i.e. experiences with illness are positively related to chance health outcome beliefs.

A posteriori t-tests shows that this belief in the uncontrollable nature of asthma was significantly higher among the control group than the three

experimental groups. However, it should be remembered that the control group's rating was 3.9 which suggests in Lau's (1982) terms that controllability is still felt to some extent. A possible explanation for the difference may be that the self-monitoring control group was provided with neither knowledge nor specific skills designed to enhance their control over asthma. This explanation is enhanced by the fact that the difference between the control group and the Compliance group is significant at the 0.01 level whilst the rating differences with the Education and Combination groups is still significant at the 0.05 level. The difference between the Control and Compliance groups seems feasible when one considers that the Compliance group received information dealing specifically with asthma medications and means of controlling the condition pharmacologically.

The Health Locus of Control subscales may be seen as indicators of a particular asthma programme's ability to alter parents' beliefs. However, it appears that none of the packages presented in the present study altered beliefs in the direction of an internal locus of control. An internal locus of control should in turn predict compliance with health behaviours. For three subscales (Self Control, Provider Control and General Health Threat) there were no differences between baseline ratings and those taken at six weeks following intervention, for any of the four groups involved in the study. If asthma programmes promoted changes in beliefs towards internal locus of control then it would be expected that the three experimental would move towards the internal end of the subscales, significantly different to the control group. This was not found in the present study. Further, the only significant change in health beliefs was in the direction of externality i.e. outcomes are unrelated to one's own behaviour. This finding was for all four groups of subjects, on the Chance Health Outcome subscale.

4-6 CONSUMER SATISFACTION

The aim of this questionnaire was primarily to obtain some indication of the utility of the present study from the subjects' perspective. While the questionnaire offered the chance to disagree with the questions, the mean ratings obtained range from 0 (neutral) to +3 (agree strongly). Of interest is the fact that the Control group rated the study in positive terms as well, yet they received no intervention of any kind. This is supported by the rating of 1.2 for question #6: "Taking part in this study has been of benefit to myself and our family" (see Table 18, Results section). The experience of being involved with their child's asthma, by recording medication levels, is apparently viewed as a beneficial activity by the control group. Although the effect of demand

characteristics on their ratings can not be entirely discounted. Thus, it seems that parents are interested in being involved in some positive way with their children's asthma, possibly suggesting the future need for increased parental involvement.

Perhaps the set of responses which deserve discussion most are those obtained in relation to question #7: "Such a programme would have been of benefit when my child was first diagnosed as asthmatic". Understandably the control group averaged a fairly neutral score (0.7) to this, given their only task was completing forms each day. The interesting ratings are from the three experimental groups. All three have recorded ratings at the positive end of the scale (2.8, 3.0, 2.7) for Education, Combination and Compliance respectively. This would suggest that the subjects in the experimental groups all perceived the information / skills received as being the type which would have made life easier when the child was first diagnosed. Therefore, parents of asthmatic children may well require more information at that early stage than is currently available from present sources. Subjects, despite the type of information received, seem to endorse the use of some form of education and / or compliance training skills regarding asthma and medication compliance. They appear to show a marked preference for such programmes to be available when their children are initially diagnosed as suffering from asthma.

4-7 LIMITATIONS OF THE PRESENT STUDY

The most obvious limitation with the present study and hence the generalizability of its findings is the small sample size employed. As noted earlier, with the present groups (N=6) it is possible for one individual to abnormally augment or diminish the group mean and hence produce skewed distributions not wholly representative of the group or of the wider population.

Evidence of the practical implications of this problem can be seen in the findings obtained for the number of asthma attacks experienced (see Figure 4). It can be seen that the Compliance group is characterized by a much higher number of attacks as compared to the other three groups. The reason for this is that a single member of the Compliance group experienced a much higher (36 compared with the Compliance group mean of 1.5) number of attacks throughout the period of recordings. In this present situation, such extreme effects make it difficult to determine the true effect of the intervention strategies, due to the small sample size. Such anomalies would effectively be eliminated with the use of larger sample sizes.

Another population characteristic of concern is the fact that all subjects in the present study were in a sense self selected. Each subject either agreed to take part or volunteered thus they may not be representative of the asthma population in general. Research (Smith, Seale & Shaw, 1984) has shown that self selected subjects tend to be more concerned about health matters and as such are already good compliers. This is borne out by the ceiling effect obtained for compliance levels at baseline for all four groups (mean = 89% across groups). This ceiling effect could also be due to a factor which limits the representativeness of the sample. This is the impossibility of controlling for prior exposure to education and/or compliance training experiences i.e. a true baseline knowledge level of asthma. A gross attempt was made to control for this by screening out any individual who had previously attended formal intervention sessions. However, by the mere fact individuals presented to the Paediatric Outpatient Department clinic, it is logical that they have encountered at least one physician who would presumably have imparted some educational / management knowledge. Similarly the present subjects varied in their length of time since the first diagnosis of asthma. Subjects ranged from those newly diagnosed to families who were diagnosed eight years previously. The length of time since diagnosis could affect attitudes and allow for trial and error to produce answers or compliance rates different to those of the newly diagnosed.

The absence of a matched wait-list control limits the drawing of firm conclusions concerning the results obtained in the present study. Such a group would neither receive intervention nor would they be involved with self-monitoring. The wait-list control would have their compliance rate assessed periodically by the data obtained within medical files concerning pulmonary functioning, visits to the general practitioner, hospitalizations and number of attacks. Any change on the given variables would then indicate more clearly that considerations outside the intervention were coming into play. As the wait-list control would not be self-monitoring, the results obtained allow a firmer conclusion regarding the power of self-monitoring as a treatment in it's own right for increasing medication compliance.

The final limitation of the present study is the level of objective assessment regarding the levels of medication compliance. Smith, Seale & Shaw (1984) state that subjects making their own recordings are reliable and accurate however it would have been more powerful to have employed an extra objective measure, beyond peak flow recordings, to assess the level of compliance. Originally it was intended to collect, from all subjects on a regular basis, the packaging from diskhalers used by the children. By comparing the spent medication blisters with reported administrations, an objective

assessment of reliability would have been available. However, during the first few weeks of data collection it became obvious that this check would be impracticable. Parents reported problems retaining the packaging which included : forgetting to save them once finished, children using them as toys and increased nuisance value in having them around the house prior to collection. Other objective measures might include bio-assay techniques, however these are not without their problems either - not the least of which is expense.

4-8 DIRECTIONS FOR FUTURE RESEARCH

In order to ensure representativeness of the sample and hence ability to generalize results, it is suggested that replications of this study employ subjects drawn from a wider base. It would be preferable for subjects to come from a non-hospital environment, possibly primary schools or the wider community. This improvement would have the added bonus of ensuring the ceiling effect was avoided by enlisting subjects who were less motivated and consequently exhibited lower rates of medication compliance i.e. the population which most needs targeting. In addition, families should ideally be enlisted upon first receiving a diagnosis of asthma in the child. This would help ensure that subjects are relatively naive to any form of education or compliance training. This in turn would give an accurate picture of the effects of intervention on novice subjects.

The overall emphasis for any replication of this study should be on obtaining a larger sample size. This would alleviate the problem of skewed distributions due to atypical individual scores. Subjects should be enlisted over a much longer period, perhaps one to two years permitting larger total numbers. This would also make it easier to run classes at differing periods when suitable numbers were available. Thus groups of twelve per experimental condition could be conducted several times per year over a longer test period. The results for each separate testing run could then be pooled to form a large data base consisting of adequately sized experimental and control groups.

When studying a wider cohort it is suggested that attempts be made to gain as much information as possible from the greater number who will inevitably drop out of the study. Failure to follow these individuals and gain information may lead to a systematic loss of information concerning the non-compliant parent who drops out of the study. Of interest here would be why they cannot complete the programme and recordings but more especially their

level of compliance. If this compliance rate is lower than for those remaining in the study it may be beneficial to ascertain any barriers to compliance which are particular to the attrition group. The wider source of information will enable more valid conclusions to be drawn concerning the barriers to effective medication compliance.

The follow-up or probe phases should also be extended. This would allow a measure of the lasting nature or otherwise of any noted effects beyond the three month period employed in the present study. As a result, effects obtained could be monitored in order to determine their stability over time and between groups. A minimum of six months or preferably one-two years would deliver more complete data. A matched wait-list control group should also be added to allow the drawing of firmer conclusions from results. This would be possible because the group would not be involved in any aspects of the study which may promote or affect medication compliance.

Finally, inclusion of a variable which details clinical outcomes pertaining to medication compliance would be valuable. This is especially so, given the finding of this present study that subjects with an 89% rate of compliance were nonetheless achieving equal to or greater than the expected norms for peak-flow recordings. The question of interest is at what level of compliance is optimal lung function achieved and its corollary is what is the effective benefit of increasing medication compliance over and above this point? One possible benefit arising from such a study would be the ability to rule out non-compliance as a critical factor responsible for the variability in treatment outcome. Thus, in cases where the child fails to improve as expected medical staff could turn their energies towards other possible causes. Some form of correlational research between the compliance rates of individuals and achievement of therapeutic goals would be beneficial, although it is realized that compliance and clinical outcome are not necessarily predictive of each other.

4-9 CONCLUSIONS

The results obtained indicate that there is no additional beneficial effect of education, compliance training or combination interventions over and above the increase due to a self-monitoring effect with this population. The intervention packages do increase medication compliance from baseline measures however equivalent significant increases can apparently be obtained by offering subjects (in this case the Control group) a simple cuing device such as a daily recording sheet. This sheet would remind parents daily of the need to

administer medications and at the appropriate times. The most significant and immediate advantage of this method over running education and compliance training classes is one of cost effectiveness.

Although the main aim of this study concerned increasing medication compliance, the results of peak-flow recordings proved interesting. These results suggest that increasing medication compliance over and above a certain point does not result in any additional improvement in clinical outcome, as measured by pulmonary function. However, a beneficial effect of the self-monitoring was evident in terms of reduced morbidity levels, namely visits to the general practitioner and hospitalizations concerning asthma.

Despite the fact that asthma programmes do not result in increased medication compliance over the effects of self-monitoring alone, the education component affected ratings of the impact of asthma on the family. Members of the education and combination groups rated impact on the family as significantly less following exposure to the education materials. Further it does appear that despite the failure to increase medication compliance the programmes offered to the experimental groups, whatever the condition, are seen as valuable by the parents. Parents in all three experimental groups agreed strongly with the statement that such programmes would have been of benefit to them when their child was first diagnosed with asthma. A change noted in terms of the parents' perceptions of asthma was that they all altered their views of asthma towards seeing it as uncontrollable. It appears that the recurring attacks engender a certain feeling of uncontrollability.

Overall, the present study has reported some interesting findings concerning medication compliance by parents of asthmatic children. They provide useful indicators for practitioners and researchers alike regarding this area of concern within the paediatric field.

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APPENDIX 1

COMPLIANCE INTERVENTION SESSIONS

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1	Comprehension of Medications	108
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SESSION 1. COMPREHENSION

Central to understanding a personal medical regimen is knowing what the medicines are and how each functions within the body.

RATIONALE FOR TAKING PREVENTERS:

BASIC PHYSIOLOGY:

The main airway (trachea) divides into two airways (bronchi) , each going to one lung.

(Show poster of healthy lungs - see Handout 1)

These main bronchi then subdivide many times into smaller airways (bronchioles) - each bronchiole ends in a little balloon like sac called alveolus. Air travels down the trachea into the bronchi, bronchioles and then into the alveoli. In the alveoli (each has a very thin lining) oxygen from the air crosses the lining and goes into the blood stream. At the same time , when breathing out, carbon dioxide crosses the alveolar lining in the opposite direction from the bloodstream to the alveoli.

The bronchi have three layers :

- (a). An outer layer of incomplete rings of cartilage, this makes the bronchus stiff and maintains the shape .
- (b). A middle circular layer of smooth muscle , which by contracting and relaxing alters the size of the bronchus.
- (c). An inner layer of mucosa (lining) consists of mucus, mucus producing glands and little hairs called cilia .

Mucus is produced all the time and traps dust and other particles . It is swept upwards to the throat by cilia and then swallowed , this is a continuous process which we are unaware of.

WHAT OCCURS DURING AN ASTHMA ATTACK?

The individual experiences a spasm or tightening of the muscles around the airways. This results in the tube becoming smaller. Next, the inner lining of the airways becomes swollen and extra mucus is produced which leads to the airways becoming even more narrow. As the attack continues, more swelling occurs . It is the swelling and mucus that makes the attacks difficult to control.

Attacks can be:

- (a). sudden, which causes distress quickly and you are forced into extra treatment.
- (b). slow starting - These are more difficult to recognize. Often there is only a bit of extra discomfort, some chest tightness during the day or waking at night due to cough. It is easier to ignore these slow starting attacks. However, delay gives more time for swelling to occur and mucus to narrow the airways therefore it is harder to control.

(Show poster of affected chest - see Handout 2)

The end result is the centre of the bronchus is narrowed. This makes the passage of air difficult and results in wheeze and trouble with breathing. The basic problem in asthma is that the airways are narrowed.

Thus, it is important to continue to use the prescribed preventer on a daily basis; even when your child appears well. This will aid in removing signs of asthma and allow a normal, active life. Medication is but one aspect of asthma care but it is very, very important and it needs to be used correctly. The principle reason asthma preventers are prescribed is to keep the airways open at a constant rate, to prevent attacks.

TYPES OF MEDICATION AND THEIR FUNCTIONS.

It is necessary to understand just what your child's medicines do and how long they need before they can take effect (see Handouts 3, 4 and 5). The time each medicine takes depends on how it is administered - administration affects the ability to reach the lungs. Medicines which are inhaled go straight to the lung tissue where they are quickly absorbed and will begin to have an effect in a minute or two. However, this can vary during bad attacks as the bronchi may be so swollen that the medicine cannot reach the small airways.

Medicine administered by mouth may not work for up to anything between 30-60 minutes (depending on the medicine). This is because it must be absorbed from the stomach and intestine before it reaches the bloodstream, which takes it to the lungs.

During an acute attack it may be better to administer an inhaled medication first then follow this up with oral medication.

RELIEVERS

Bronchodilators are medicines which relax the bronchial muscles and open the airways, thus making breathing easier. During an attack the small muscles around the bronchial tubes tighten ; bronchodilators relax these muscles so the tubes can open up again . Thus air gets into the air-sacs. Bronchodilators give immediate relief therefore they are used in treating attacks but they can also offer long term control if they are taken everyday . This long term control is only in terms of rectifying the narrowing but not as to the cause of that narrowing .

Bronchodilators can come in different forms : liquid, tablets, capsules, inhalers or injections. The following are classed as adrenaline-like, due to their chemical composition being similar to the adrenaline our body produces.

Name: Berotec, Bricanyl, Ventolin

Safety: These are safe if taken as prescribed, there will be no harmful effects even after years of taking. Children on Ventolin syrup or tablets may experience slight shaking, nervousness or excitability. This is due to a slight stimulant effect on the Central Nervous System, it is not harmful and does not last. These effects are less likely if an inhaler is used.

THEOPHYLLINES

These relax the bronchial muscles but they relieve asthma much slower than other bronchodilators, they take hours. Theophyllines are not usually the only form of treatment prescribed to control asthma, they are used in conjunction with other medications. They are often prescribed as treatment for attacks when inhaled substances are of little use, also they are very valuable for night symptoms.

Name: Nuelin, Nuelin-SR, Theodur, Theo-24, Somophyllin, Aminophylline

Dose: It is important to only take the dosage prescribed by your doctor. You must never administer more during attacks. It is necessary to take these medicines every day , even when your child appears well , as the airways narrow between attacks.

Rapid form: This type is quickly absorbed and some effect is apparent after one hour , by 4-6 hours another dose is needed. This fast acting form is available in tablet forms.

Slow release: This helps overcome the problem of remembering doses. The tablets or capsules/sprinkles are absorbed slowly therefore

they stay in the bloodstream for 8-12 hours. Take two per day. They are available in tablet form (Nuelin-SR & Theodur) as well as capsule/sprinkle form (Nuelin, Theodur & Somophyllin). The sprinkles must be taken prior to meals, given on a small quantity of soft food such as yoghurt - this is to avoid them being crushed .

Very-slow release: Capsules (Theo-24), this must be taken one hour before food. The reason for this is that food interferes with the absorption of the Theophylline. However Theo-24 has not gained general acceptance yet and may not be prescribed.

All other Theophyllines are to be taken after food. The slow and very - slow release tablets and sprinkles have a special coating to allow the Theophylline to be absorbed at a constant rate. This means that they should not be crushed, by doing so all the medicine will be absorbed at once .

Safety: High doses of Theophylline can cause side-effects, therefore doses should not be increased without your doctor prescribing such. Side-effects may include ; nausea, indigestion, headache and shakiness . These may indicate that the dose is too high, therefore a blood test is required. Theophylline should not be mixed with certain medicines because the amount of Theophylline in the blood may change . If it rises, side-effects may ensue ; if it decreases it may be ineffective. There is a therapeutic band for Theophylline use which is specific to each individual. Thus, if a dose is missed you must not administer an extra dose to "catch-up".

PREVENTERS

These medicines prevent asthma triggers from making the asthma worse and help prevent attacks. Triggers e.g.) smoke, cold cause the inner lining of the airways to release chemicals. These chemicals make the bronchial muscle spasm or tighten, thus the airway narrows. Preventers are able to stop or at least lessen the release of these chemicals, but they work slowly.

It is important to realize that the chest and breathing do not feel immediately better after taking preventers - only relievers can do this. Once treatment is begun, the improvement begins slowly and it may be a matter of weeks before the medicine has it's best effects. It is necessary to take the preventers at regular intervals, on a daily basis - even if the child is feeling well.

When a child's asthma worsens, the dosage of the preventer must not be increased to more than the prescribed amount. They do not help during attacks. Preventers do not relax the bronchial muscle, therefore they cannot

relieve the attack. Also, airways are more sensitive during attacks so preventers may irritate them and produce a cough.

Name: Intal - capsule powder for inhalation
Vicrom - pressure pack inhaler (puffer)

Dose: 3-4 times per day, at regular intervals. Even when feeling well. Take an extra dose 15 minutes before exercise. Take 1-5 minutes after a reliever inhaler, which relaxes the bronchial muscle.

Safety: These are very safe because the medicine works on the lung surface, therefore it doesn't reach the bloodstream. They may occasionally produce a throat irritation but gargling with water after inhalation will help.

INHALED STEROIDS

These are prescribed when bronchodilators plus Intal are not sufficient to control asthma. They are low dose cortisone medicines, which are similar to the natural steroids in our bodies. Natural cortisones do two things:

- (a). allow the body to cope with stress, extra is produced during injury
- (b). help the body keep a correct balance of water, sodium and potassium. (however the inhaled steroids do not act so.)

Inhaled steroids are powerful preventive agents which prevent the irritating chemicals from being released by the airways. They also help prevent the inner lining of the airways from becoming swollen and stop mucus from building up. These preventers cannot treat an attack because they do not open the airways which are closed - they are anti-inflammatory. Further, they do not give any immediate relief and are of no use before exercise.

Name: Aldecin, Becloforte and Pulmicort - in puffer form.
Becotide in powder diskhalers.

Dose: Taken at regular intervals, because the medicine is slow acting. This must be everyday, even when the child feels well. They need to be given twice per day. Also, they need to be taken regularly for several weeks to build adequate protection against attacks.

Safety: These are very safe, as the amount of cortisone in each puff or capsule is very small. The medicine works at the lung surface therefore so little cortisone enters the bloodstream there is very little trace of it. Usual doses of inhaled steroids do not produce the effects associated with long-term, regular treatment of steroid tablets; nor do they harm the airways.

ORAL STEROIDS AND INJECTIONS

These can act as a reliever because they treat the underlying inflammation which gives rise to the irritable airways. However, this is only when high doses are taken during an attack. They can also act as preventers when small doses are taken regularly for troublesome asthma.

Steroids are very strong medicines which prevent the release of chemicals which cause bronchial spasm. They can be life-savers during bad attacks. The steroids also stop mucus from building up in the airways and reduce the swelling which inhibits breathing.

During an attack, the swelling of the airways can stop the inhaled medicines from working. This is because the medicines are stopped from reaching all parts of the lung due to narrowed and possibly blocked airways. Oral steroids are able to reach the airways via the bloodstream, thus controlling swelling and enabling the mucus to be cleared. For this reason injections and short courses of tablets are very important in treating attacks. By unblocking and soothing the airways they help to make bronchodilators more effective and breathing gradually becomes easier. However, it does take several hours (4-24) for the steroids to work.

Although the medicines are very potent and may produce side effects, when used carefully they are invaluable. They are prescribed for acute severe attacks, where there is instability in the airways or when there is an upsurge in symptoms (often after viral respiratory infection). However, with some chronic severe asthmatics it may be necessary to provide continuous tablet taking, which is carefully monitored by the doctor. The doctor will try to establish the lowest possible effective dose for each patient, to minimize side-effects. However this is only possible if the patient continues the other medications at regular intervals.

Name: Prednisone in tablet form
Hydrocortisone in injection form

Dose: These need to be taken exactly as prescribed. Except for at the start of the attack, the total daily dose is always taken in the morning. This is because the morning is when the body normally produces the cortisone for the day. The result is less disturbance to the body's natural rhythm.

Short-term dose: These are high dose prescriptions for a short time (usually 5-10 days) for severe asthma attacks. As the attack comes under control, the doctor will gradually decrease the dose over several days. You must never stop this treatment by yourself, even if the attack seems better. This is because the anti-inflammatory effect of the

steroid treatment requires several days to be effective. If the treatment is stopped prematurely, the problem won't be settled and the attack will reoccur. It is essential never to miss scheduled doses of inhalers and Theophyllines, even if the steroids seem to be controlling the asthma. By remaining on the other medications, the asthma has a better chance of becoming milder.

Long-term dose: These are lower doses taken over a long period for chronic severe asthma. It is dangerous to suddenly stop taking steroids after months of treatment. This may leave the body unable to make enough cortisone by itself. When the time is right, your doctor will gradually stop the cortisone over a period of months. This will allow the body to produce it's own cortisone again.

Safety: Steroids are very useful medicines which are fairly safe if used as prescribed. There are usually no harmful effects with short courses (1-2 weeks), if they are only used a couple of times per year. The common side-effects are generally only seen in people taking steroids for years or at very high doses for many weeks. These side-effects include : increased appetite, fattening of the face, change in the mood and possibly in energy levels as well (hyperactive-type behaviour). There may also be some slowing of the child's growth due to interference with the growth hormone secretion and tissue sensitivity. This is not a problem if the prednisone is prescribed for alternate days. The time of concern is if the growth slowing occurs at puberty. This stops the normal pubertal growth spurt and if the bones fuse at this stage then the growth cannot be made up. Generally speaking, children will reach their correct height unless they are continually taking the medicine for over a couple of years.

Any side-effects can be kept to a minimum if the dose of steroids is kept as low as possible and is taken on alternate days. Thus, it is important to continue taking all other medicines, using an inhaler correctly and measuring peak-flows daily. These steps will aid the doctor in prescribing the lowest effective dose. Only a few people need steroids on a long term basis. If your child needs to be on frequent short courses of steroids then the asthma is not well controlled, you will need to see the doctor regularly.

ANY SIDE-EFFECTS OF THE MEDICATION ARE OUTWEIGHED BY THE SIDE-EFFECTS OF NOT TREATING THE ASTHMA. UNTREATED ASTHMA WILL SLOW GROWTH.

MEDICATION USAGE

No matter how advanced or well made a medicine is, it cannot perform to its best potential if it is not administered correctly. This is especially important as far as inhaler technique is concerned. If the inhaler is not used correctly then there is little chance of the medicine reaching the small airways - where it is needed. Even when the puffer inhaler is used correctly, only about 10% will get into the airways. The remainder is either swallowed or breathed out. One of the major errors is to press the puffer before starting to breathe in. You can check your child's technique by looking for any "mist" of medicine around the mouth or top of the puffer. Perhaps the most common error is to rush the breath in after firing the inhaler. It is best to take several seconds to fill up the lungs. A slower breath in allows the narrowed/blocked airways time to open, thus the medicine can reach all parts of the lungs. Also it is important in helping to reduce the amount of the medicine which hits the back of the throat. Further, it is more helpful to then hold your breath for around 10 seconds, this allows the medicine to stay in the lungs to help the asthma.

PUFFER-INHALER:

- 1) Shake the inhaler vigorously
- 2) Hold the inhaler vertically. Breathe out slowly and gently till the lungs are comfortably empty.
- 3) Tilt head back, close lips around the mouthpiece. As you slowly start to breathe in press the metal canister down firmly. Continue to breathe in deeply.
- 4) Remove the inhaler from mouth, while continuing to hold your breathe for as long as is comfortable - approx. 10 secs. Breathe out gently.
- 5) If another dose is required, wait at least one minute then repeat.

INTAL SPINHALER

- 1) Hold the Spinhaler upside-down, gripping the mouth-piece. Unscrew the body.
- 2) There will be three parts : a body with coloured sliding tube, propeller and a mouth-piece with steel spindle.
- 3) To load - Hold the mouth-piece downwards and fit the propeller onto the spindle so that it can spin. Place the coloured end of the cartridge firmly in the propeller.
- 4) Screw the body back onto the mouth-piece, making sure it is firmly in place.

5) Holding the spinhaler with mouth-piece downwards, slide the coloured tube down - only once -as far as it will go.

6) Then slide the coloured tube back. The cartridge is now pierced and the spinhaler ready for use.

7) Check that the mouth-piece is still firmly screwed on. Hold the spinhaler well away from mouth and breathe out fully.

8) Insert the mouth-piece with the guard against the lips, grip mouthpiece with teeth and breathe in deeply and strongly so that the powder will reach the lungs. Hold the breath for a few seconds while removing the spinhaler away from the mouth. Breathe out. Never breathe out through the spinhaler.

9) Repeat instructions 7 and 8 three or four times. Any powder remaining is of no importance. Throw away the used cartridge and return the spinhaler to the container to keep it clean and dry.

DISKHALERS - Ventodisk and Becodisk

1) Remove the mouthpiece cover. Hold the diskhaler firmly in a level position.

2) Lift the lid as far as it will go, return it to the closed position. The needle on the lid has now penetrated one of the blisters on the disk and the diskhaler is now ready for use.

3) Breathe out fully, place the mouthpiece in your mouth, keeping the diskhaler level. Tilt head slightly backwards. Take care not to cover the holes in the side of the mouthpiece. Breathe in slowly through your mouth - but as deeply and fully as possible. Hold your breath for a few seconds before breathing out.

4) Slide the mouthpiece tray out and in. The next dose is now available.

BRICANYL TURBUHALER

1) Unscrew and lift off the cover. Hold the inhaler upright with the blue grip at the bottom.

2) Load the inhaler with a dose by turning the blue grip as far as it will go and then back to the initial position.

3) Breathe out. Never breathe out through the inhaler.

4) Put the mouthpiece between your lips and breathe in deeply through your mouth.

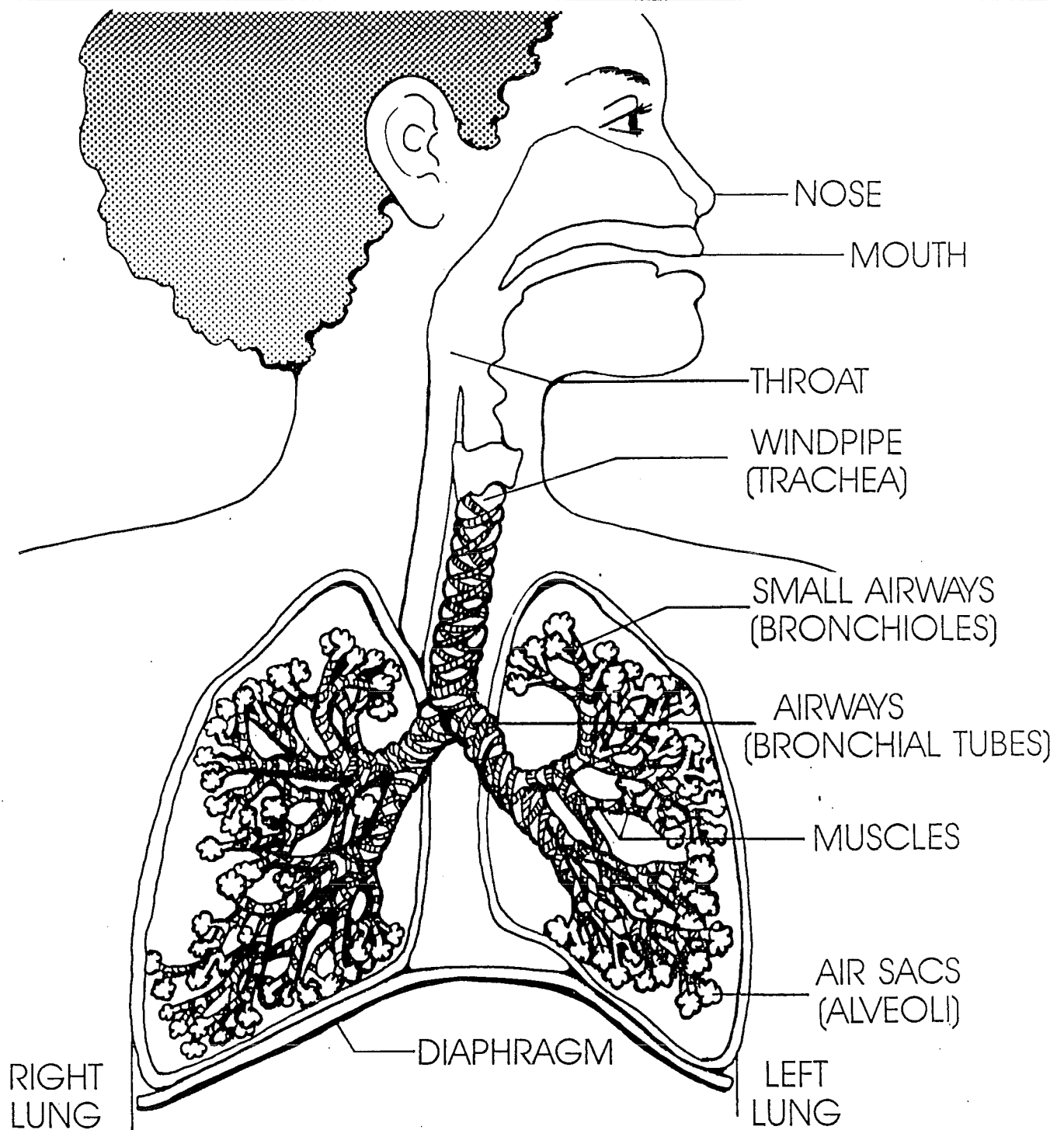
5) Remove the inhaler from your mouth and hold your breath for 10 seconds or as long as possible. Replace the cover.

6) Check the dose indicator under the mouthpiece regularly to make sure the inhaler is not empty.

- When the indicator shows a red mark there are approx. 20 doses left. When the red mark has reached the lower edge of the window the inhaler is empty.

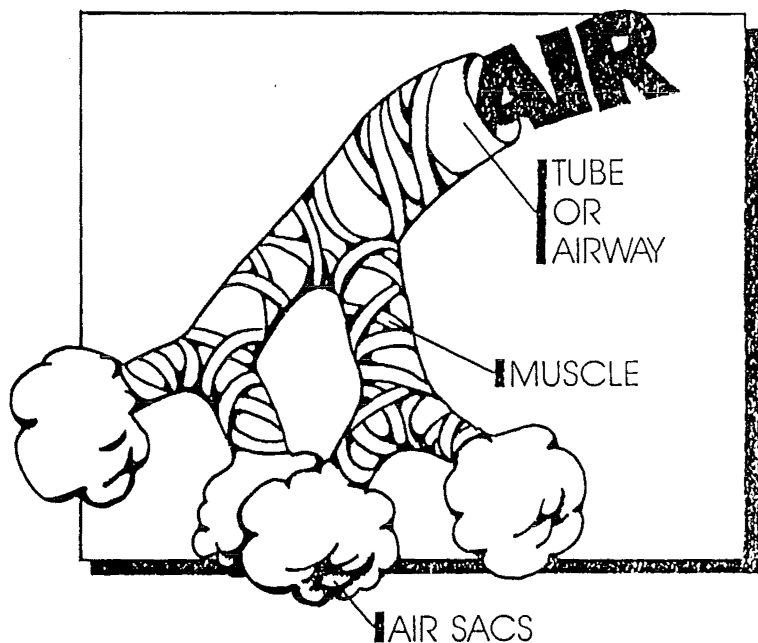
HANDOUT 1

NORMAL LUNGS

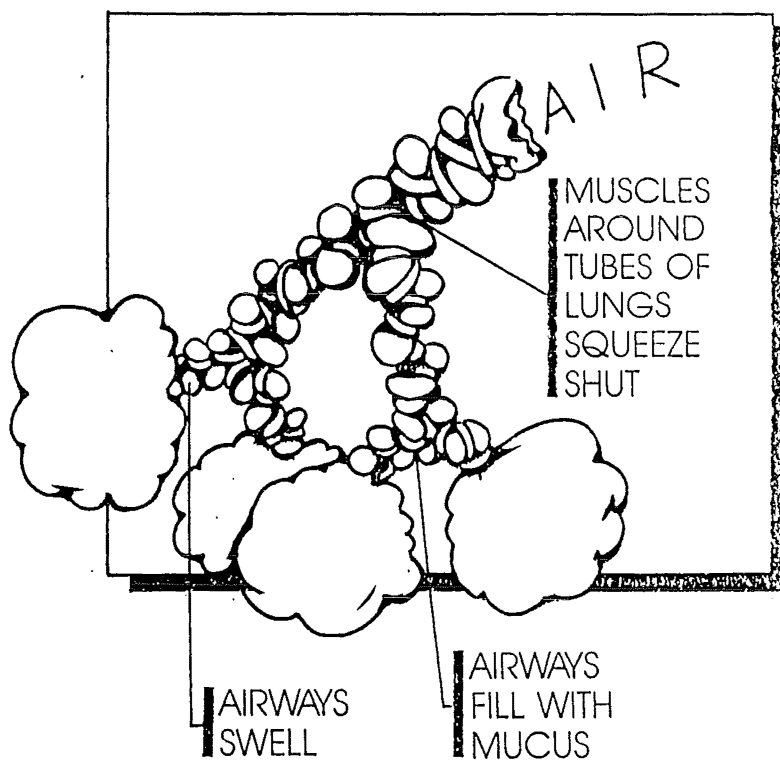


HANDOUT 2

LUNGS **BEFORE** AN ASTHMA ATTACK



LUNGS **DURING** AN ASTHMA ATTACK



COMMON QUESTIONS ABOUT ASTHMA MEDICINES

Why do you take medicines for asthma?

Asthma medicine keeps the airways open by causing the muscles around tubes in the lungs to relax.

How can you make medicine taking easier?

Have your child take liquid medicines with soda, juice or water.

Have your child take pills or capsules with apple-sauce or jello; or cut pills in half so they are easier to swallow.

How does the doctor decide which medicine your child should take?

Each person has special medicine needs. Check with your child's doctor about your child's medicine needs.

If your child has mild asthma and very few attacks, he/she may only have to take short-acting medicine at the first sign of wheezing to keep the wheezing from getting bad.

If your child has more severe asthma and frequent attacks, he/she may take long-acting medicines that are taken every day.

Old medicines should be discarded when a new one is prescribed, unless the doctor says otherwise.

Are asthma medicines dangerous?

People do not become addicted to asthma medicines.

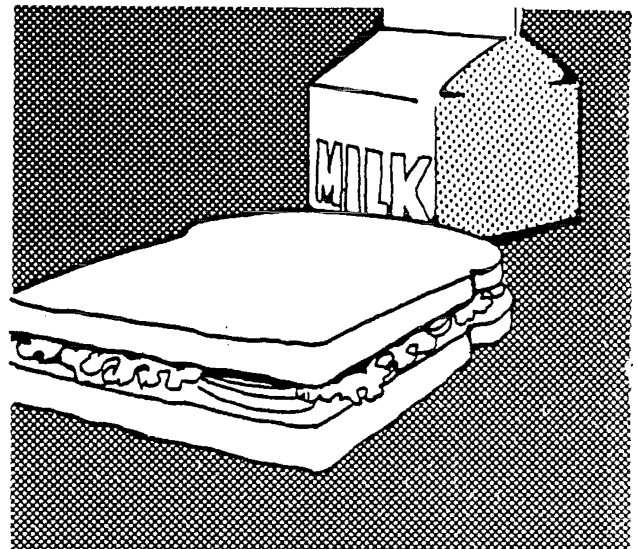
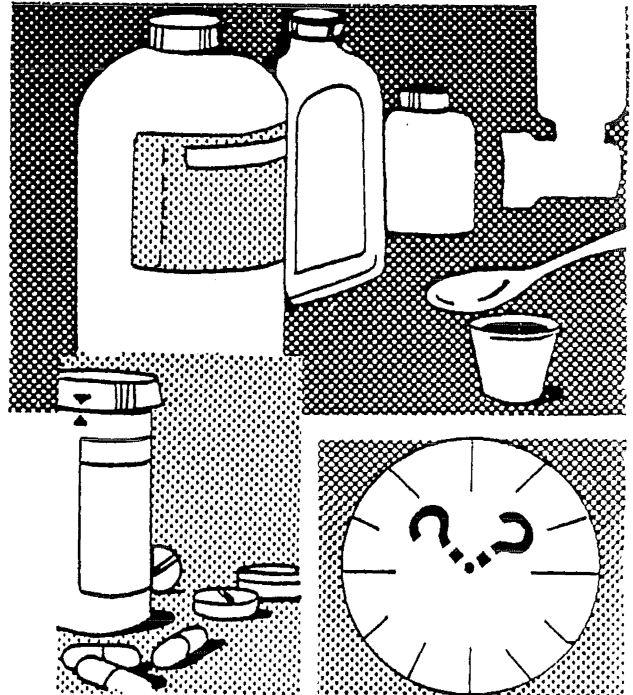
The most common asthma medicines, if taken properly, do not cause long-term side effects.

If steroids are taken properly, in consultation with a doctor, they too are safe.

What are possible side effects and how can they be controlled?

Some side effects are nausea, vomiting, or nervousness. If these occur, have your child take the asthma medicine with milk or food.

If side effects do not go away, talk to the doctor about adjusting the dose or changing the medicine.



ASTHMA MEDICATIONS

A BRIEF DISCUSSION FOR PARENTS

HOW MEDICATIONS WORK

When discussing medication there is one thing that always seems important: "How long does it take for a medication to work?" That generally depends on the way the medication is taken.

Asthma medications that are taken orally, either in capsule form or liquid form, can take 30 minutes or more to become effective. Liquid medications can be absorbed into the bloodstream a little faster than tablets or capsules; but 30 minutes is a good estimate for either.

An injection, such as adrenalin, gets the medication into the bloodstream much more quickly. It takes only about 5-10 minutes for adrenalin to work.

An inhalant-medication that is breathed directly into the lungs gets absorbed into the bloodstream rather quickly. If the inhaled medication is a bronchodilator, bronchospasm is generally relieved in only a minute or two. There may be a problem with this type of medication, however. When the lungs are badly constricted and plugged with mucus, an inhalant may not reach the lung tissues very well. Also, inhaling a medication may cause coughing, which may make the problem worse. **And not all inhalants are intended for prompt relief of bronchospasm. Inhaled steroids or Intal/Vicrom, for example, should NEVER be taken during an asthma attack.**

The following is a brief discussion of four different kinds of asthma medications: bronchodilators, inhaled steroids, Intal and oral steroids.

BRONCHODILATORS

Bronchodilators are drugs that relax the bronchial muscles. Common bronchodilators include any of the Theophylline drugs and other drugs like Berotec, Bryicanyl and Ventolin.

Bronchodilators are available in liquid, tablet or capsule. Others are in inhalant form and others are intended to be administered by injection.

INHALED STEROIDS

Becotide is a steroid medication that can be inhaled directly into the lungs, but it is **not** a bronchodilator. Other inhaled steroids are Aldecin, Becloforte and Pulmicort. Steroids work by reducing the swelling in the bronchial tubes, and they also enhance the action of bronchodilators.

Inhaled steroids should **NEVER** be taken during an asthma attack as these can cause coughing and actually make the attack more severe. Inhaled steroids are supposed to be taken as **preventive** medication, usually on a routine, daily basis.

Inhaled steroids prevent bronchospasm from occurring, but they won't stop bronchospasm once it occurs.

INTAL AND VICROM

These are other drugs that are inhaled. Intal and Vicrom should be taken only as a preventive measure.

These work by preventing allergens from triggering bronchospasm.

During an acute attack, Intal and Vicrom should NOT be inhaled.

ORAL STEROIDS (STEROIDS TAKEN BY MOUTH)

Prednisone is a steroid, but prednisone is taken in tablet form rather than by an inhaler.

Prednisone or another oral steroid is generally prescribed when asthma is particularly difficult to treat. If your child is on oral steroids, he or she should always continue to take his or her regular bronchodilators, because oral steroids work by enhancing the effects of bronchodilators.

Since oral steroids are strong drugs, doctors generally don't like to put people on them unless there is no other choice.

FACT SHEET ON **ASTHMA MEDICINES**

Asthma medicines are one of the most powerful tools you have to control your child's asthma. By working with the doctor to find the medicines that help your child most, you can prevent asthma attacks. This fact sheet will help you and your child to talk to your doctor about asthma medicines.

NAMES	HOW THEY WORK	TIMING	POSSIBLE SIDE EFFECTS	HANDLING SIDE EFFECTS
Theophylline type bronchodilator drugs Aminophylline, Nuelin, Nuelin-SR, Theodur, Theo-24, Somophyllin.	Open tubes in the lungs	Starts to work about one hour after being taken; stops working after five or six hours; some capsules last 8 to 12 hours.	Stomach ache, vomiting Fast heart beat, headaches, dizziness, difficulty sleeping, increased urination, seizures (rare)	Take the medicine with food. See the doctor.
Other bronchodilator drugs Berotec, Ventolin, Bricanyl	Open tubes in the lungs	Starts to work 15 minutes to one hour after being taken; effects begin to wear off after about 4 hours.	Shakey hands or legs Fast heart beat	Often goes away in a few weeks, but try taking the medicine with foods or milk. See the doctor.
Cromolyn Inhaler (Intal) Cromolyn Powder (Vicrom)	Prevents the symptoms of asthma	Must be taken for a few weeks in order to work; do not take during an attack.	Dryness in throat	Drink water or juice after inhaling the medicine.
Oral Steroids Prednisone,	Open tubes in lungs, increase effectiveness of other medicines	Controls symptoms 6 to 12 hours after taking; not for immediate relief of attack.	For Prednisone, stomach aches With continued use of Prednisone, slow growth, weight gain, bone problems, dependency on the medicine	Drink a glass of milk with the medicine. See the doctor.

SESSION 2. COMMUNICATING WITH THE DOCTOR.

As we now know, the principle reason that asthma medication is prescribed is to keep the airways open at a constant rate. The key to safe use is proper prescribing and this is based on good communication; between child, parent and doctor. The parent is best placed to detail the child's condition to the doctor so that s/he can prescribe the best medication. The parent needs to be able to give the doctor accurate and detailed information regarding: symptoms, frequency of these, situations they occur in and any reactions to the medications the child may have.

Remember, to care for your child adequately at home you need to understand what is involved in continuing care. For this you need information from your doctor, if you and your doctor exchange information then your child will get the best care.

The aim of this session is to help parents identify and resolve problems in dealing with doctors and the giving and receiving of information. Thus we need to develop effective ways to communicate with doctors. (See Handout 6).

PROBLEMS

The first thing we need to do is to identify the problems that you as a parent have in dealing with doctors.

Exercise #1 - I'd like you to call out problems you've had or areas of frustration you've experienced. I'll list these on the board.

Possible problems:

- feeling anxious
- scared to ask questions
- not understanding information
- forgetting questions you have.

Other problems you may not have thought about but which are of concern to doctors are:

- not taking the child to your G.P. after s/he is discharged from hospital
- seeing G.P.'s only during a crisis (thus the doctor has no idea of baseline asthma)
- some parents change or stop medication without telling their doctor.

STEREOTYPES - HOW WE VIEW DOCTORS

Exercise #2 - Can everyone tell me what comes to mind when they think of a doctor ? I'll write the descriptors on the board.

Most of us have ideas about what doctors as a group are like and how we expect them to behave. This is a stereotype i.e.) a generalization of a group; it involves categorizing doctors into group membership on the basis of information received. Thus when we encounter a doctor it is possible that we do not respond to them as an individual. Instead we may interpret them and their behaviour on the basis of previous experiences. Such experiences affect what we remember of the doctor and consultations, which in turn affects our future behaviours and attitudes.

How many people described a doctor above in terms of positive things?

After a number of visits to the doctor we end up with a group of attributes associated with doctors and use these to organize information about the individual. The images that we hold onto most tend to be our first impressions and if these are bad then they tend to stand out even more. This is because they are not what we expect from doctors, seeming strange and thus become prominent. However these prominent images may not reflect the behaviour of all doctor.

Because we've built these stereotypes of doctors, we tend to associate certain activities with consultations and behave accordingly. An example of this would be your recollection of restaurant visits - book, arrive, sit, read the menu, order etc. - you know how to behave because you've done it all before. Thus, when you eat at a new restaurant you call on your general restaurant ideas and behave accordingly. Similarly, with doctors, we tend to build up an idea of what happens during a consultation - book, wait, describe symptoms, be examined etc. Now when we see a new doctor, we call on our old ideas and have the same expectations of events. But what if we didn't like our other doctor or had a bad experience? Here we tend to repeat our past behaviours because we expect all new doctors to be the same. Thus if we previously said nothing or were scared by the experience we will tend to be the same again.

Now just to recap, so far, we've looked at : how we see doctors and their behaviours, why we tend to see them as such and more importantly, the problems we have in dealing with them. What we need to do now is formulate some skills and techniques we can use when dealing with doctors. However, let's first look at ourselves as the patient or person dealing with the doctor.

EXERCISE #3 WHAT MAKES A GOOD OR BAD PATIENT?

Let's write down on the board the characteristics of both good and bad patients as you see them. Here it may help to think about your own experiences with doctors.

CHARACTERISTICS OF A GOOD PATIENT. (e.g.s)

asks questions of the doctor and nurse

gives the doctor information

discusses problems re asthma, medicines etc.

complains when necessary

CHARACTERISTICS OF A BAD PATIENT. (e.g.s)

is passive and accepting

doesn't let doctor know when s/he can't understand

gives socially acceptable answers

Which of these do you think are most likely to result in the best care for the child ?

Do you disagree with any ? Why ?

SOLUTIONS TO COMMUNICATION PROBLEMS

We've found some difficulties to do with doctors visits and problems in getting the information we need. Now, let's try and find some solutions.

Anxiety - This may in part be due to the stereotypes we hold about doctors (e.g.) intelligent, superior and having prestige. We could describe anxiety as an unpleasant emotional reaction of inner apprehension. It can be a reaction to a situation where we feel powerless and unable to cope with or influence the situation. Our view of the situation plays a big role in how much stress we experience. The facts of the situation may not be threatening but if we interpret them as so then the anxiety level will increase. Similarly, our feelings of competency and confidence in our ability to handle the situation will affect the severity of the anxiety we experience.

Thus the first step to having a better relationship with your doctor is to deal with this anxiety. Not only does the anxiety make you feel bad but it can also interfere with the learning process. If the doctor is telling you about asthma medications and you are very anxious, you will not take in the facts as well as under normal circumstances. A little bit of anxiety can actually

"heighten" the senses but above a certain level it becomes counterproductive and interferes with your concentration.

We shall now look at two methods of combating these negative effects of anxiety.

(a). "Belly-Breathing" - This is a relaxation technique you can do easily and unobtrusively as you sit in the waiting room. The rationale is that you cannot be anxious and relaxed at the same time - they are incompatible. Sit comfortably and breathe with your diaphragm (place your hands on your stomach and feel it rise and fall). This allows much more air in and helps to calm us; when you exhale, purse your lips and breathe out. Just sit quietly and do this for a few minutes as you are waiting. Let's try this now.

(b). "Cognitive Restructuring" - The second method focuses on the stereotypes we discussed earlier. Often our beliefs about people and situations have an effect upon how we behave in response to them. If we believe something to be true, then we will expect to see these traits being displayed and take more notice of them. The result is that we will adopt a method of behaviour to deal with this. So, if we perceive doctors to be powerful and superior we will pick up evidence to support this and act in a fashion consistent with those beliefs i.e.) submissive and yielding. This of course leads us to feel ill at ease when encountering that individual or situation - which tends to result in anxiety. If we try to alter our perceptions of doctors then we can begin to influence our behaviours. This takes longer to learn and use effectively than the relaxation.

However if you look at the stereotypes you hold and slowly try to alter them, then you are on the road. The main thing to do is to alter your perception of the doctor, from being totally in control and superior. Try to see him/her as a person who has some knowledge which you can use, in partnership, to help control your child's asthma. Thus, you can begin to see yourself as not being powerless but rather, as having necessary, detailed information about your child's condition. The idea is to alter your thinking from "I just sit here" to "I can help by giving accurate information".

By using these coping strategies you may start to overcome the feelings of inadequacy and powerlessness which often lead to anxiety.

INTERACTING

Following on from this is a point which doctors see as essential to the patient-doctor relationship - the need for input by both parties concerned.

To help your child best, the doctor needs as much information as possible regarding symptoms, side-effects, frequency of attacks etc. Only you can give this, so you must be an active participant in the consultation. Be aware of and tell the doctor about any changes since your last visit - this is your chance to be a **partner**. The doctor will ask questions to establish your child's physical status but you should not expect him/her to anticipate all your concerns. If there is anything that you do not understand or are worried about it is best if you voice your concerns. It is important that you are not passive, just sitting and agreeing. The worst thing you can do, it is potentially dangerous, is to say you understand something when you are really confused. None of us likes to appear "slow to understand" but the doctor must be made to realize that medical details are not easily understood by lay-people.

This of course requires you to be assertive, which takes a while to achieve. Assertive does not mean aggressive. Rather, it means that you take note of your feelings and needs, making them known to the doctor. If s/he uses jargon or big words, say you do not understand and get him/her to repeat things in terms you are familiar with. Keep asking until you are clear about what s/he is saying and you understand it fully. It is the doctor's job to explain things to you so that you can understand.

Lines of communication

This two-way interaction is important in helping you to establish what these lines are and also to establish your personal crisis plan. It is important to know these things well ahead of when you will need them. Talk to your doctor and find out how you can get answers to any queries, outside office hours or without an appointment. Remember, asthma can occur and/or worsen suddenly; so it is best to have these things worked out in advance. e.g.)

- can you ring for a prescription refill ?
- is the nurse able to answer your questions ?
- Will the doctor see you immediately during an attack ?

By establishing these facts and discussing emergency situations you will feel more comfortable and be more confident in emergencies.

Visits between attacks

Try to see the doctor more as a preventive agent and not just a crisis-stopper. If you visit regularly, the doctor will know what is "normal" for your child i.e.) how s/he copes between attacks. This in turn allows the medicine to be reassessed, if your child is coping well then perhaps the medication can be reduced. So, by visiting between attacks you can be sure your child's medicine

is the most suitable. Remember, asthma does change so such visits can be of benefit to both you and the doctor.

DIFFICULTY IN REMEMBERING

This refers specifically to times in the doctor's office when you have several questions to ask but invariably you forget some. The most effective means of countering this is to take a list along. You should spend some time, before going to the clinic, thinking about what you want to know or have explained. By writing these down you will be able to talk over everything you want - and things will probably go more smoothly. Most doctors will not mind at all if you do this; it shows you've thought about the visit and condition. Don't be embarrassed about taking a list with you, it may even save some time as you will be more organized. However, if you have a particularly long list it may be an idea to tell the nurse then she can make allowances with the schedule.

RIGHTS OF THE PATIENT

Your relationship with the doctor is obviously that of physician - parent but as we discussed earlier it should also be a partnership. Yet another way of viewing the relationship is that you are a consumer. You have gone to the doctor for a service and as such you have certain rights - and of course responsibilities.

Your rights include:

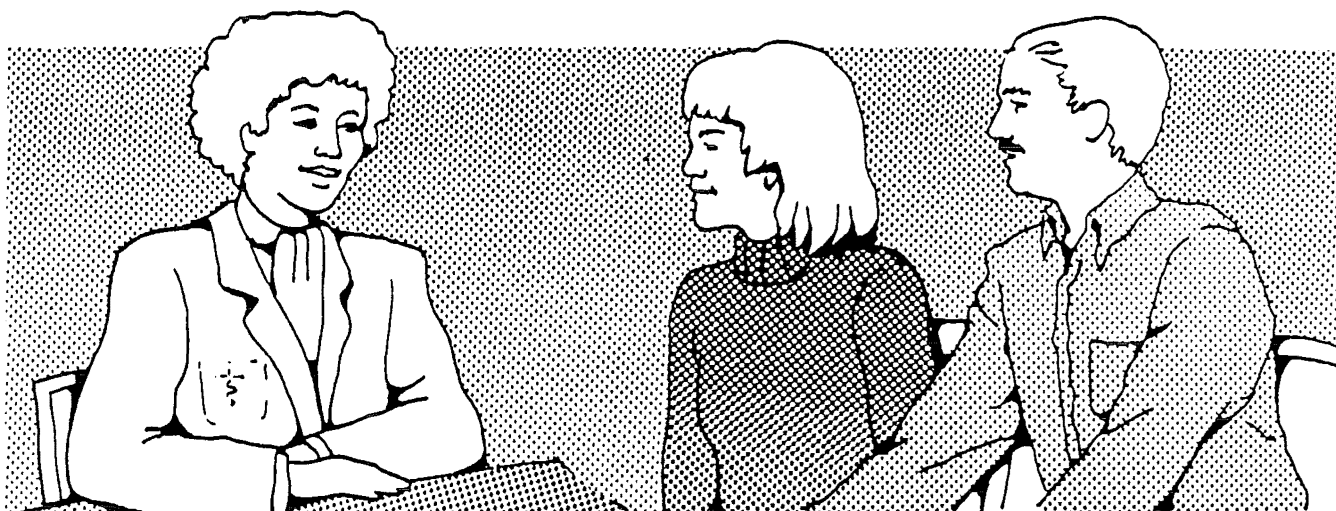
- Informed consent is necessary before any treatment begins. This means the doctor should explain the condition, what can and will be done to treat it, any risks or side-effects plus any alternative, viable treatments.
- You are entitled to considerate and respectful care
- You may ask and expect to receive any relevant information you desire.

Along with these rights are some obligations on your part:

- To be honest with your doctor regarding treatment compliance, side-effects and if you do not understand. If you are not completely honest, it is very difficult to prescribe appropriately for your child.
- To tell the doctor if there is any change in your child's health or circumstances which may affect his/her medications.

HANDOUT 6

COMMUNICATING WITH THE **DOCTOR**



The doctor makes some decisions about your child's health based on what you and your child tell him/her. When you go to the doctor, prepare to exchange information with him/her. Some parents have found these things to work and offer the following suggestions:

1. Take along a translator, if you need one.
2. Write down the questions you want to ask the doctor and keep asking the questions until you get answers you understand.
3. Provide information about your child's asthma to the doctor. Tell the doctor:
 - How your child has been feeling since the last visit and if he/she has had any attacks.
 - If your child wheezes or coughs when exercising.
 - What other things or events seem to trigger wheezing.
 - What specific medicines your child takes, their dosages, and how often they are given.
 - If there are any problems with the medicines such as side effects or scheduling problems.

It is important to feel comfortable in communicating with your child's doctor.

SESSION 3. UNDERSTANDING PRESCRIPTION LABELS, USING MEDICATION SCHEDULES

Last session we talked about communicating with doctors. If we can quickly recall the content, you will remember that the two most important things were:

- Treating the relationship as one of partners and thus actively participating.
- Being assertive enough to ensure the doctor is aware of your feelings and problems.

How do you feel about these ideas now ? Has anyone had a chance to put them into action ? How did it go?

UNDERSTANDING PRESCRIPTION LABELS

Confusion may arise with instructions given by your doctor, concerning the administration of asthma medications. The causes of this confusion may be varied but usually include: a degree of anxiety on the patient's part , medical language used by the doctor, time constraints etc.

Often the only tangible explanation you are left with is the label on the medicine container. Unfortunately the detail and quality of these labels may vary from chemist to chemist. It is suggested that if parents fully understood what the short instructions on these labels were intended to mean , this would help overcome the problem. What follows is a guide to the meaning of the instructions intended by your doctor when prescribing asthma medications.

It will be of great help to you if you take down the meanings which are relevant to your child's medicines. There are sheets provided for this purpose (see Handout 7). The idea is that you will then be able to have the sheet at home for reference at any future stage.

EXERCISE #1: Let's take a few moments to discuss, in a group, the problems you may have encountered with labels.

- are they self-explanatory?
- do they differ from chemist-chemist?
- any other feelings or experiences?

MEANINGS INTENDED BY YOUR DOCTOR

RELIEVERS : VENTOLIN, BEROTEC, BRICANYL

The dose depends on individual requirements, generally it is:

2 puffs or one blister, to be taken 4 times per day at regular intervals.

Most children will be on the powder form.

"TAKE 4 TIMES PER DAY" - If possible this means every 6 hours.

However, practically this means 4 equally spaced doses (between the child's getting up and going to bed). Thus, a 7am-7pm lifestyle for your child means : the first upon arising, second at 11am, third at 3pm and the fourth at 7pm before bed.

"EXTRA DOSES AS REQUIRED" -

- (a). If your child suffers from exercise induced asthma s/he should take an extra dose before exercising. This will reduce the chance of asthma resulting.
- (b). It is safe to take a few extra doses of a reliever if wheeziness and chest discomfort return in-between regularly timed doses. However, if this persists then it may indicate that your child's asthma is not well controlled - you should see your doctor.

THEOPHYLLINES

These must only be taken in the dosage prescribed by your doctor.

Remember, there is a therapeutic band for every individual child - below this, the medicine will not work and above it, side-effects will result. Never give more during an attack. Theophyllines need to be given everyday, even if your child feels well, as the airways tend to narrow between attacks.

"TAKE AFTER FOOD" - This means the tablets must be swallowed within 1/2 hour of having a meal -(not just a biscuit). The reasoning is that food helps to counter any possible side-effects.

"TAKE 4 TIMES PER DAY" - This, means that the medicine should be taken at regular times which are evenly spaced. Thus, a 7am-7pm lifestyle for your child means the first dose is given on awakening. The second will be given at 11am, the third at 3pm and the fourth at 7pm. This is due to the fact that theophylline is quickly absorbed by the body. Some effect is apparent after 1 hour but by 4-6 hours later another dose is required.

"TAKE 2 PER DAY" - This refers to the slow release version, the Theophylline is absorbed much slower by the body and will remain in the

bloodstream for 8-12 hours. The tablets should be given 12 hours apart e.g.) at 7am and 7pm.

"TAKE ONE TABLET WHOLE" - This refers specifically to the slow release tablets, Nuelin-SR and Theodur. These tablets have a special coating to prevent immediate absorption. If the tablet is crushed or chewed, the coating will be broken and the slow release impossible.

"SPRINKLE CAPSULE ON FOOD" - For Nuelin and Theodur sprinkles, which need to be given twice per day. The instructions mean to sprinkle the contents onto some soft food. The sprinkles should not be used on any food which needs to be chewed, this will crush the small special- coated granules. This special coating allows the Theophylline to be absorbed at a constant rate over a given time period. The soft food e.g.) yoghurt will also help mask the taste if your child finds it unpleasant. This medicine should be given about 40-50- minutes before your child has a main meal - the meal may interfere with absorption of the Theophylline.

PREVENTERS

For these medicines to be of any value to your child they must be given everyday at a regular time, even if your child appears well. The instructions concerning the times of administration are similar to above e.g.) "TAKE 4 TIMES PER DAY" - each dose should be equally spaced within the time your child is awake. The important thing to remember with preventers is that they will only work well if they are given at regular times, everyday.

REMEMBER:

These medicines prevent attacks they do not treat them!

INTAL

"TAKE ONE CAPSULE..." - This means that the contents of one capsule should be inhaled as is prescribed. It is important to know that your child can use the inhaler correctly.

VICROM - Used mainly with older children.

"TAKE 2 PUFFS, 4 TIMES PER DAY" - The dose should be spaced equally apart. The canister should be well shaken before inhalation and the 2 puffs should be spaced one minute apart. Again it is important to be sure your child is using the correct technique.

"TAKE FOLLOWING A RELIEVER" - If this is used with either Intal or Vicrom medications, it means there must be at least a 1 minute gap between using the reliever and then the preventer. This is so that the reliever has time to relax the bronchial tubes, which will in turn allow the preventer to reach it's target.

"TAKE AN EXTRA DOSE BEFORE EXERCISE" - The intention here is for it to be given about 15 minutes before your child begins exercising.

INHALED STEROIDS - Aldecin, Becotide, Becloforte, Pulmicort

These do **not** have the same effects as oral steroids. If you remember last session we discussed how inhaled steroids actually contain very little cortisone. Further, as this works directly on the lung surface only negligible amounts enter the bloodstream.

"TAKE 2 PUFFS 4 TIMES PER DAY" - The timing instructions are the same as above, with the canister being well shaken immediately before use.

ORAL STEROIDS - Prednisone

"TAKE ONCE DAILY" - This specifically means the medicine should be taken in the morning, soon after arising. The reason is that this is the usual time the body produces it's own version of these medicines - thus the body's natural rhythm is kept as normal as possible.

"TAKE AFTER FOOD" - This means to give the medicine within 30 minutes of having a meal.

As we said at the beginning of this programme, there are two fundamental reasons why asthma medications are not complied with. The first has to do with comprehension difficulties and the second with errors in administration.

We have covered the area of comprehension during the last two sessions, as well as the first half of today. For the remainder of this session and during our final session next week, we shall look at the errors made in administration - as well as ways to overcome them. Today we shall deal with the problem which affects us all at some time or other - forgetting. What I want to do is introduce you to the theory of memory and learning, what some of the problems are here and show you a device to overcome these - a referral chart.

REFERRAL CHART

This is a readily accessible device which plainly sets out the prescribed schedule of medicines for your child (see Handout 8). That is; what to take,

when and how much. The idea is that the format is easy to read and it should be prominently displayed so that you encounter it often.

The uses of this chart are:

- it aids memory and learning by detailing essential information in easily comprehended form.
- it emphasizes the importance of taking medicines on time. Think back to our session on preventer medicines and how they need to be taken at regular times to ensure a steady level of medication.
- it reminds you of the correct dose to administer. If you recall, Theophylline has a therapeutic band and doses outside of this will result in side-effects or be of no use.
- it helps establish and promote responsibility on the child's behalf. This is due to the availability of the information in situations which are common to the child's activities.

MEMORY AND LEARNING

Most of us take for granted the fact that we can remember things and occasionally forget some items. Yet our memory is actually a complicated thing which has its own special rules for operating at peak efficiency.

a) The intention to learn something is actually irrelevant to the amount learned. Let's remember back to our high-school days. How many can recall having a test in two days time and diligently pouring over the material to be learned - yet - no matter how you wanted to learn it all, it just didn't "stick" ? Probably what was affecting your performance was the way you were trying to learn it. The important aspect is the way you process the information.

b) Central to good memory is the level of meaning and organization in the material to be learned. Think about trying to learn a list of 20 jumbled words - how much success would you have ? Now what about if they meant something to you e.g.) 20 items found in the kitchen. Would your score be improved ? The list would now have an overall meaning i.e.) kitchen utensils and they would be familiar. Now, what if these meaningful words were organized into smaller categories e.g.) things used to eat with, foodstuffs etc. ? Chances are that the meaning and the organization would allow you to process the information much better than if it were a jumbled list.

So, to recap all this, memory works better if the things to be recalled are set out in; small basic units which are self-contained and these units have some internal organization i.e.) a logical self-ordering structure.

BASIC PROBLEMS WITH MEMORY

Emotional Factors - negative emotions can hinder learning and affect your recall. The prime example of this would be anxiety, especially as it relates to being in the doctor's office.

Let's imagine you're in the surgery, feeling rather anxious about being there and specifically your child's latest asthma attack. The doctor is busily telling you about the new medicine and how to administer it but your child is still wheezing badly and crying.

How much do you think you will take in ? - (comments)

A study was done on just this problem in England. The researchers recorded the consultation and then asked the mothers questions about what the doctor had told them. The main finding was that the mothers could not recall most of what was said to them, in fact they were surprised about the information contained on the tapes. As we have said before, a bit of anxiety can be helpful but there is a level above which it interferes with learning.

Further to this, anxiety can affect our recall simply because it is often accompanied by extraneous thoughts. When we try to recall what we learned in the surgery we also remember the anxiety involved and unfortunately this tends to trigger off other melancholic thoughts e.g.) the day Lassie died. This is an example of extraneous thoughts that can accompany negative emotions.

By using a referral chart you can get over this problem of anxiety to a great degree. This is because all the necessary information about the medicines is down in print and can be referred to at any stage.

Thus you do not have the pressures of trying to learn something immediately in a strange environment (surgery). Further, the chart is displayed in the privacy of your own home which is a much less stressful situation.

CONDITIONS OF LEARNING

Such things as the frequency of encountering material and the opportunity of rehearsing it can also affect your memory. The difficulty with learning in a doctor's office is that you only get the one chance to go over the material, then it's up to you to remember. The more novel the material is, then the more you need to encounter it for good recall. If you imagine encountering details of asthma medications for the first time you can understand how relevant these factors are. After leaving the surgery, the only opportunity to encounter that material is the next consultation - whenever that is.

However, by having all the information on your referral chart you are able to go back to the material as often as you like or feel is necessary. Thus, you have the opportunity to learn at a pace which is suited to you - free from pressures.

CHARACTERISTICS OF THE LEARNING SITUATION

A factor which aids memory, is being able to recall the information in the same situation as you learned it in. Again, if we can think back to our schooldays when we sat exams, we might be able to see the sense in this.

Imagine having an exam in your usual classroom where you learned the material. You encounter a difficult question but can remember Mr. Bloggs taking that specific lesson. What should be possible now is to beam in on the specifics of that class e.g.) Bloggs wore a blue shirt, he was standing in that corner, he was talking about... ah!

Do you see how the learning situation has helped clarify things; both by giving you pointers and also by excluding irrelevant material?

Now, let's put that in asthma terms. If you learn about medicines at the doctor's, then it will be more difficult to recall the information if the emergency occurs at home. This is because the conditions of learning give no pointers or retrieval cues. Consider the same emergency situation but you have learned the medication details from your referral chart at home. This time you can have familiar surroundings as retrieval cues because the attack is occurring in the same place you learned the material in.

SUMMARY OF RATIONALE FOR USING REFERRAL CHARTS

- you can learn in an anxiety free atmosphere
- there are no pressures to learn it all at once
- you can refer to it as often as you require
- learning is in the situation you will most often have to recall the data in

Finally, the referral chart is a good example of a much suggested form of learning. The PQ4R method points out the factors which are central to good recall I will now go over this on the board and we can talk about how the referral chart sets these principles out.

- *Preview:* read over the information for each unit (medicine)
- *Questions:* turn the structuring into questions e.g.) when do I give this?
- *Read:* go through the information and answer the questions you have made

- *Reflect*: read over the information, think about it all and relate everything to asthma and medications
- *Recite*: Recall all the relevant information (aloud if you like) and answer your questions again
- *Review*: go over everything once more, recall the important things and try your questions once more

Discussion: on each of these points.

You can now see how this referral chart is able to help you to remember facts about your child's medication schedule. If you place it in a prominent place e.g.) on the fridge door, you will encounter it often. This will then help in learning the material, as well as overcome problems associated with remembering.

ABOUT YOUR MEDICINE

Put your schedule somewhere so you can always see it—on the refrigerator door, in the bathroom, or on your bedroom door.

MEDICINE SCHEDULE			
What is the name of each medicine I take?	What does it look like?	When should you give it?	How much should you give?

REMEMBER

DO NOT give medicines that your doctor has not prescribed for your child. It may not be right and it could make him/her sick.

Take the right amount of medicine at the right time.

Tell your doctor if the medicines make your child sick, or tired, or keeps him/her awake. The medicines can be changed.

KEEP THE PRESCRIPTION FILLED.

PERSONALISED MEDICAL INSTRUCTION SHEET**MEDICATION****INSTRUCTIONS**

1. _____

MEANING

MEDICATION**INSTRUCTIONS**

2. _____

MEANING

MEDICATION**INSTRUCTIONS**

3. _____

MEANING

SESSION 4. SKILLS TO AID RECALL.

This final session will continue to look at how we can overcome the problem of forgetting to administer medicines correctly. Last week we learned how memory "works" and some of the problems associated with recall. The method we used to aid our recall was the referral chart.

Has anyone had a chance to use their chart?

Did you find it a help? - perhaps you might like to share your experiences with the group.

Today we will look at:

- (a). problems associated with taking medicines within the family setting.
- (b). remembering, by associating the need to take medicine with a routine activity.
- (c). tailoring medicine schedules to fit your individual family activities.
- (d). using an asthma diary, to record symptoms etc. and aid in communication with your doctor.

PROBLEMS IN THE FAMILY.

I'd like to read you a short story about a child and his medicine. Once I've finished, we'll look at the specific difficulties in the story. I'd like you to think about possible solutions to these problems, as well as any for problems your own family might have and then we will discuss these as a group.

DAVID AND HIS MOTHER

- D. Hi mum, I'm home. I'm going to get a drink; O.K.?
- M. Sure, but make sure you take your medicine.
- D. Later mum, I'm going to watch T.V. with Pete now. We have to see Star Trek.
- M. Later is too late. You have to take the medicine on time, to keep your airways open.
- D. Look mum, I don't have any asthma now, so why do I have to take the medicine ?
- M. Remember what happened when you missed your medicine last week? You started to wheeze badly.
- D. But it tastes terrible and I'm sick of taking medicine.

M. That's enough David. Come here and take this medicine right now!

D. Wait until the next commercial, O.K. ? Just one more commercial.

Problems in this story

- David "has "to see T.V.
- he doesn't have asthma now
- the taste is terrible
- he's sick of taking medicines

EXERCISE #1

What can David and his mother do to make medicine taking easier ?

Think about possible solutions and in a moment we will talk about them.

Discussion period

Please call out solutions to the above problems which I will write on the board. We will then look at individual family problems in a similar way. (The aim is to have all subjects talk about how they would solve the problems; hopefully promoting the value of social support networks for problem solving as well).

Possible solutions to be mentioned for the story:

- Make viewing T.V. conditional upon taking the medicine
- Explain the relationship between not taking medicine and the onset of attacks. This is best done when both of you have more time and put it in terms your child can understand. REMEMBER, children work in the "here and now" i.e.) they pick up on immediate reinforcement and negative consequences. So it may take a while to explain how not taking the medicine today will result in an attack several days later.
- Be inventive in efforts to mask bad tastes e.g.) give the pill with ice-cream or a drink. If swallowing medicines is a problem then check whether it is O.K. to cut the pill in half or crush it - REMEMBER, some pills must not be crushed.
- Discuss with your child the need to keep taking medicines regularly, talk about how they help to keep the airways open at a constant rate.

HOW TO DEAL WITH PROBLEMS IN THE FAMILY:

ASSOCIATION VALUE

The problem with medicines is that they are something which we have to get used to taking or administering. Because they are not part of our usual activities it is easy to forget to give them. One method we can use to aid our memory is to have our medicines associated with normal, routine activities e.g.) keeping the pills by the toothbrush. Thus, when we come to do the routine activity we will be reminded of the need to have the medicine.

The reasoning behind this is: when we are learning something new, it is easier to pick-up and then recall the details if they are associated with a behaviour or object we are already familiar with. So, when we think about or encounter the familiar things then the new information will spring to mind as well.

EXERCISE #2

I am going to write a list on the board, the one thing each item will have in common is that they all have three letters.

List: jfu rwi cat tcm hen qnd dog

Have a look at the list, then tell me which items you think would be easier to recall. Why do you think those items would be easier to recall?

On the most basic level, these are all composed the same i.e.) each has three letters. Yet three of them stand out immediately - cat, hen, dog - and the reason for this is that they all have an association value.

What comes to mind when you see the word - cat?

- possible descriptors: furry, "miaow", drinks milk, chases mice etc

Although the word is just a grouping of letters, we have associated a certain meaning to this particular grouping. Through experience with cats as pets and everyone calling these animals by that name we have come to associate the characteristics of that animal with these letters.

A possible explanation for how this works was put forward by Anderson (1980) in his Network Theory. He suggests that our memory is made up of many millions of "nodes" which are interconnected, like a network. Each "node" represents a particular idea or memory and it is connected or associated, by the learning process, with other "nodes" which are relevant. Thus, when our memory is activated regarding "cat" then the energy from this

activation process tends to set-off nodes which are associated with it e.g.) chases mice.

In terms of asthma, by associating medicines with routine activities then the activation of the routine "node" will spread to all other associated nodes. So, using the earlier example, by thinking about cleaning your teeth you activate associated "nodes" e.g.) bathroom, bedtime, pyjamas, asthma pills by the sink etc.

- Do you see how the associations can be used to aid our memories concerning the taking of medicines?

Exercise #3 - Discussion period

It is quite possible that some of you have been using similar strategies on your own but just didn't put a name to what you were doing. Practical examples of this you might like to try at home are:

- keeping pills by the toothbrush
- a note on the wardrobe, for first thing in the morning
- having an inhaler in your child's school lunchbox
- a note taped to the inside of the lunchbox to remind to take medicines

Has anyone tried any of these suggestions?

How did you find them as memory aids?

Would you like to share your experiences with the group?

BEHAVIOURAL SOLUTIONS TO FORGETTING

There are other, more direct methods of helping you to remember to take medicines. The idea here, is to employ methods which bring to awareness the fact it is time to take the medicine and hopefully you will then administer the medicine. The following are simple but effective means to achieve this:

- set an alarm clock, set the alarm to ring at the appropriate time. This will force you to get up and turn it off and then bring to mind the reason it was set i.e.) time to administer the medicine.
- place a clock on the T.V. where it is obvious to all and continuously encountered. Hopefully this will then keep the need to administer the medicines to the fore of your mind.
- get others in the family to remind you. This can often be turned into a game with siblings of the asthmatic. Explain you are having difficulty in remembering to give Johnny's medicine and could the kid's remind you

at 6 p.m. ? A little bit of praise for their reminding you will ensure the kids will let you know again the next time.

Any one of these skills can be used to aid your remembering to administer medicines or, indeed, a combination of these skills may be more effective for your own situation. Have a try with any or all of them and select whichever is most suitable to aid in reminding you.

TAILORING

The aim of this section is to promote the idea of fitting medication administration into the family's schedule. The rationale is that if the administration times are convenient and not competing with other family activities, they will be easier to remember. How many times have you been busy cooking tea and been so completely active that you forgot to administer the medication at the usual time ? The problem here is that you have two different things competing for your mental resources and attention - cooking tea and the administration of medicine.

There are many examples of such occasions in each family's life. If you consider the pressures of ballet classes, sports practices etc. , you can see how there are regular activities which interfere with medication administration. The problem is two-fold, you may forget altogether or else the administration may be delayed. Remember back to an earlier session and you may recall the need to give asthma medications at **regular** intervals. If the medication is not administered at regular intervals then it cannot be completely effective.

What I'm suggesting is that each of you take a look at you family's schedule of activities and see if there is any conflict with medication times. If there is, then what you need to do is to fit the medication times around this schedule - so that both can be regularly accommodated. Thus, hopefully the family can continue with it's activities and your child can receive the correct medication dosages. A point to remember here is that you need to be aware of the special requirements of each medicine. Before making any changes to your schedule, go over the earlier material to see what you need to be aware of. Here, I'm talking about the need to take certain medications with or before food etc. If you have any queries or aren't completely certain then talk to your doctor about any changes you have in mind.

Another thing you can talk to your doctor about is the possibility of simplifying your child's medical regimen. In some cases it may be possible to reduce the amount of medication required by your child - depending on his/her condition. The simpler a regimen is, then the easier it will be to

remember. However, NEVER alter the amount or type of medication you give your child without first consulting your doctor.

ASTHMA DIARIES

The final aspect we shall look at in these sessions is the use of an asthma diary in your home. This is a recording sheet which allows you to detail, on a daily basis, the condition of your child's asthma and symptoms (see Handout 9). Thus, you will have a clear record of how well the asthma is under control and more importantly, whether there is any change in his/her condition. The following are benefits to be gained by using a diary:

- 1) You are all aware that there are two different types of attacks a) the immediate starting, acute and b) the slower starting one which builds up over days. The asthma diary allows you to see whether there is any change in the child's symptoms and alert you to the possibility of a forthcoming attack. This in turn allows you to take steps to deal with the asthma before it becomes too bad; also, you are not caught by surprise.
- 2) The best control of asthma is obtained by good prescribing and the diary contains valuable information for just this purpose. The doctor can see, at a glance, how your child has been since the last visit. This then gives a strong platform to work from concerning the current problem. Also, by continually recording this data your doctor can gain valuable information regarding how your child is coping between attacks. Such information about non-crisis periods lets your doctor know whether the medication should be altered or if it is adequate for your child's current needs.
- 3) By reading through the diary before a consultation you can be perfectly clear concerning what you want to discuss. This enables you to overcome some of the nervousness and possible memory problems. Further, it allows you to fulfil your role as a partner in caring for your child's asthma - remember, the doctor has the expertise but you have the intimate knowledge of your child.

The diary has been designed so as to allow for quick recording of relevant information which may have occurred over the preceeding 24 hours.

Lets have a look through the example together and go over how to fill out your asthma diary.

Peak Flow: there is space to record readings both in the morning and afternoon of each day. Just fill in the reading from the meter.

- Night Wheeze:* if this was present, enter a number in the box which relates to the level of wheeze experienced.
- Night cough:* record as for night wheeze
- Today's wheeze:* record as for night wheeze
- Activity today:* insert the number which best describes your child's level of activity
- Running nose:* insert the number which best describes this symptom
- Asthma attacks:* for the number per day, insert the number experienced during the previous 24 hours
- if your child stayed in bed or missed school due to asthma on a given day then tick the relevant box
- Medications:* list the medications as prescribed by the doctor and write in the amount given each day
- Comments:* this allows you to make a note of anything you may wish to discuss with your doctor, when it happens.
Thus, you have a record of any problems, feelings etc. for later reference.

DATE	
DAY	
PEAKFLOW best of 3	AM before medicine
	AM after medicine
	PM before medicine
	PM after medicine
NIGHT-WHEEZE none =0 woke 2-3 times = 2 some = 1 awake most of night = 3	
NIGHT- COUGH none = 0 moderately bad = 2 some = 1 severe = 3	
TODAY'S WHEEZE none = 0 moderately bad = 2 some = 1 severe = 3	
ACTIVITY TODAY <div style="display: flex; justify-content: space-between;"><div>normal = 0</div><div>could only walk = 2</div></div> <div style="display: flex; justify-content: space-between;"><div>couldn't run far = 1</div><div>couldn't do anything = 3</div></div>	
RUNNING NOSE none = 0 moderate = 2 mild = 1 severe = 3	
ASTHMA ATTACKS	<div>number per day _____ stayed in bed _____ missed school _____</div>
ALL MEDICATION TAKEN	<div>1 _____ 2 _____ 3 _____ 4 _____</div>
PARENT'S COMMENTS eg) side-effects , feelings problems	

APPENDIX 2

EDUCATION INTERVENTION SESSIONS

SESSION		PAGE
1	Feelings / Information about Asthma	150
	Handouts : 10, 11	157
2	Activities and your Child	159
	Handouts : 12, 13, 14	162
3	How to Manage Asthma Attacks at Home	166
	Handouts : 15, 16	171
4	Controlling Asthma Triggers	173
	Handouts : 17	176

Scanning note: Many of the subsequent pages have the left-hand side missing. Due to the way the original was bound we were unable to improve on the quality.

PARENTS' SESSION ONE:

FEELINGS ABOUT ASTHMA/BASIC INFORMATION ABOUT ASTHMA

Topic: Feelings About Asthma

Purpose

- To let parents get to know each other and establish common bonds.
- To enable them to share experiences and problems in managing asthma.
- To help them understand their roles in teaching and learning about asthma.

Objectives

Participants will:

- ❶ Express concerns and ideas about asthma to each other.
- ❷ Talk about the feelings they have during an asthma attack.
- ❸ Value each other as a source of information and support.
- ❹ Discuss the idea that keeping calm and relaxed will help parents and children manage asthma better.

Process

Hello. My name is _____. We are here today to share information, ideas, and concerns about asthma so that you can learn more about taking care of asthma at home.

To help us get to know each other, turn to the person to your left and introduce yourself. Tell each other a feeling or a question you have about asthma. Then do the same thing with the person on your right.

■ GIVE PARTICIPANTS 5 MINUTES FOR INTRODUCTIONS.

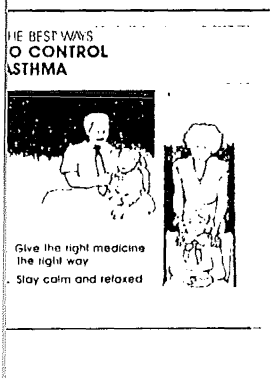
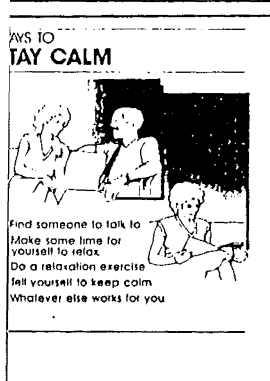
Now I'd like each of you to tell us a feeling or a question about asthma that your right- and left-hand partners brought up with you.

■ WRITE QUESTIONS AND FEELINGS ON THE FLIPCHART. Ask the following questions, and ask for ideas about how to solve problems raised. Use the problems/solutions chart below to suggest points participants don't make.

ALKING
INTS

QUESTIONS TO
GENERATE
DISCUSSION

- Has anyone else ever had that (problem, experience, concern)?
- What do you do about it? What else?
- What other questions, concerns, or advice do you have about asthma?
- What are some of the feelings you have when your child has an asthma attack?
- Why do you feel that way?
- What do you do about it?
- How does that help?
- What else could you do to cope with these feelings?



Problem

I feel panicky or start to cry when my child has an attack.

I feel guilty that my child has asthma instead of me.

No one else in the family has asthma. Where did it come from?

I feel like asthma is such a burden that I just can't cope anymore.

Solution

■ DISPLAY POSTER 1.

Find ways to stay calm, such as:

- Have someone to talk to.
- Make some time for yourself to relax.
- Do a relaxation exercise.
- Tell yourself to keep calm.

It is normal to feel this way—many parents do. Remember that asthma can be controlled by giving the right medications and staying calm.

■ DISPLAY POSTER 2.

Good asthma control now reduces the likelihood of future problems.

It appears that asthma is more likely to occur in some families than in others. Some doctors believe that certain people may be born with extrasensitive airways, although we still need to learn more about why this may be so. While we don't know exactly how people develop asthma, we do know how to control it.

Using the four ways to stay calm may help. Many of the things you learn in this course will help you make asthma less of a burden in your day-to-day life.

SUMMARY

Parents and children with asthma have similar problems and concerns. As we have seen in our discussion, parents also have the answers to many of these problems. For example, we've heard that staying calm is important for managing asthma.

Parents can make it easier for each other by sharing this kind of information and experience. What I'll be doing is adding ideas to the ones you raise and clarifying information about asthma.

Tips for Teachers

● Almost every parent will have some good solutions to the problems discussed. Reinforce each person's solution, which you can do simply by restating it.

● If parents express negative feelings, summarize them. For example, Mrs. Jones says she feels like running away when her child has a bad attack.

Accept the statement in order to normalize it. Say, for example, "It's certainly not unusual for parents to feel that way."

Get others to talk about similar feelings by asking, "Has anyone else ever felt that way? What feelings do you have in that situation, Mrs. Torres?"

When problems are expressed, encourage the group to solve them by asking "What can Mrs. Jones and Mrs. Torres do to cope with their feelings?"

- Some parents may express no problems or negative feelings about their child's asthma. They may be reluctant to discuss problems for fear of being judged a bad parent or being held responsible for the child's poor control. Don't try to force parents to acknowledge problems. Accept the response and move on.

- The role of teacher/facilitator is to ensure that basic health messages are conveyed during the activity. You can introduce the message by saying, "Many parents have told us that another way to cope with asthma is . . ." or "Most physicians who treat children with asthma believe . . .".

Topic: Basic Information About Asthma

Purpose

To ensure that all participants have the same fundamental information about asthma.

To address common questions.

To continue group interaction about asthma.

To reinforce the idea that parents have useful information to share with each other.

Objectives

Participants will:

- Define asthma as it is currently defined by physicians.
- Discuss the early signs, triggers, symptoms, and course of asthma as well as the role emotions play.
- Discuss attitudes and beliefs about life with asthma and asthma management.

Process

One way to help control asthma is to learn more about it. Today we're going to discuss some of the facts about asthma.

ASK THE FOLLOWING QUESTIONS. Raise ideas from the key points column that participants don't suggest, and clarify misconceptions.

Concept

Asthma physiology

Questions

What happens in the body when your child has an asthma attack?

What else?

What happens to the lungs?

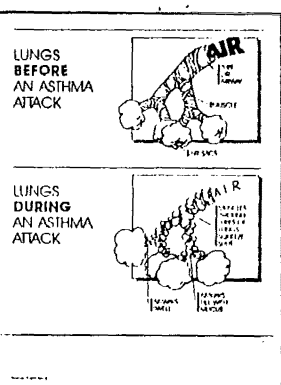
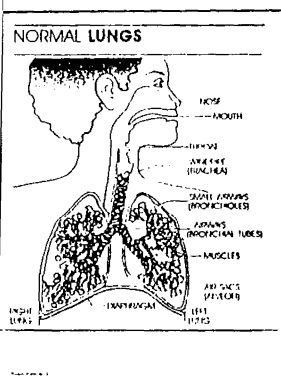
What is produced in the lungs that makes breathing difficult?

What else makes breathing difficult?

Points to Raise

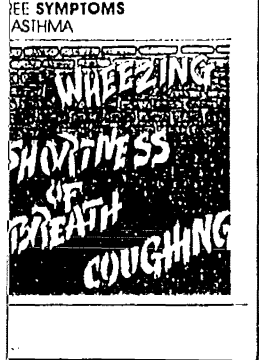
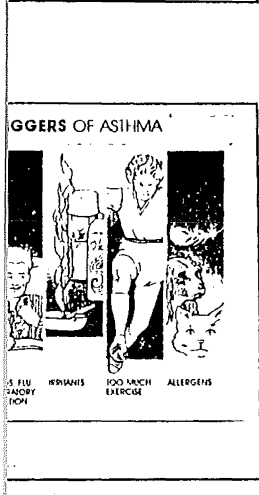
DISPLAY POSTERS 3 AND 4.

In asthma, it is difficult to move air in and out of the lungs because the muscles around the tubes to the lungs squeeze shut. Mucus is produced in the airways, and airways swell, so air has a hard time getting through.



TALKING POINTS

QUESTIONS TO GENERATE DISCUSSION

Concept	Questions	Points to Raise
	<p>Symptoms</p> <p>How do you know when your child is having an attack? What are your child's symptoms? What other asthma symptoms can a child have? How serious is asthma?</p>	<p>■DISPLAY POSTER 5. When air has a hard time getting through, your child may: —Wheeze. —Be short of breath. —Cough. Asthma attacks can be severe, but it is rare for a child to die from asthma. Asthma symptoms can be controlled by giving the right amount of medicine at the right time.</p>
	<p>Triggers</p> <p>What makes you child get an attack? What else? What other things trigger asthma attacks?</p>	<p>■DISPLAY POSTER 6. There are four kinds of asthma triggers: —Colds and infection. —Too much exercise. —Things that irritate the lungs, e.g., perfume, hairspray, smoke, air pollution. —Things children are allergic to, e.g., dog or cat hair, dust, food, plants, and pollen from grass and trees. Most household triggers can be controlled. Following certain guidelines, exercise can be very helpful to a child with asthma. Exercise does not have to trigger an attack. Using the right medicine before exercise can also help your child stay active.</p>
<p>Emotions and asthma</p>	<p>Can a person's emotional makeup cause asthma? How do emotional upsets affect asthma? What can you do to help your child deal with symptoms triggered by emotional upsets?</p>	<p>A person's emotional makeup will not cause him or her to develop asthma. But emotional upsets can make asthma symptoms worse. Children can learn to control asthma symptoms triggered by emotional upsets using relaxation exercises.</p>

Concept	Questions	Points to Raise
Duration of asthma	Has anyone else in your family had asthma? Do they still have it? Do you think your child will continue to have it? Why or why not?	The duration of asthma is different for each child. Many children will not have it in the future. Others will have it, but it will be mild. Some children will continue to have it with the same intensity. Doctors believe that the better children control their asthma, the less trouble they will have with it as adults.

SUMMARY

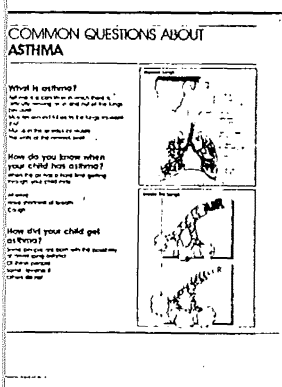
It is clear from our discussion that you already know a lot about asthma and how to control it.

REINFORCE MAJOR MESSAGES BY WRITING THEM ON THE FLIPCHART AS YOU SUMMARIZE.

We've learned that some ways to control asthma are:

- To give the right amount of medicine at the right time.
- To give medicine before heavy exercise (after talking to your child's doctor).
- To have the child do relaxation exercises.

If asthma is controlled, children can lead normal lives. They can participate in sports, other physical activities, and social events. And, the better you and your children control asthma now, the less trouble it will be in the future.



DISTRIBUTE HANDOUT 10

You can take this sheet home to remind you of some of the basic asthma facts we've talked about today.

Tips For Teachers

- Use participants' own words, as much as possible, to talk about asthma.
- Involve all participants in this discussion by asking each parent questions relating to his or her child. For example, if Mrs. Rodriguez says her child gets asthma symptoms around dogs, ask the next person, "What triggers your child's asthma, Mrs. Escobar?" You can also encourage parents to talk about similarities and differences in their children's asthma.
- Parents are likely to raise more questions and concerns about asthma in this session. Here are some common problems with suggested solutions you can elicit from the group or offer yourself.

Problems

Parents may say their child looks like he or she is going to die during an attack.

Some parents may have unusual descriptions of the origin of their child's asthma. For example, they may say that the child was "born with a cold" and has had asthma ever since.

Parents may discuss the fact that their smoking triggers the child's asthma, yet they are unable to stop smoking.

Parents may also express frustration about being unable to eliminate other triggers.

Solutions

Ask others if they have similar feelings. Ask if they know someone who died from asthma. Reassure parents that although it is not impossible to die from asthma, it is rare that it happens.

Ask other parents if they have similar associations. Reassure parents that this is coincidental, and repeat the basic message that asthma is a condition in which a person develops "extrasensitive airways."

Ask other parents if they have this problem. Ask for solutions. Some solutions are: smoke only in one room, smoke outside the apartment, and don't smoke around the child.

Ask for solutions. Emphasize that each solution is a "success story." Tell parents that a future session will focus on triggers and how to deal with them.

Activity: Belly Breathing

Purpose

To introduce exercise as a way parents and children can help each other stay calm during an asthma attack.

Objectives

Participants will:

- Value belly breathing as a way to stay calm during an attack.
- Demonstrate their ability to do belly breathing correctly.

Process

Belly breathing is a technique parents and children can use to stay calm during an asthma attack. Can anyone show us how it's done?

■ IF NO ONE VOLUNTEERS, DEMONSTRATE THE TECHNIQUE.

Belly-breathing exercise

1. Sit up straight on a chair (your child can also lie on a bed or the floor and bend his/her knees).
2. Place both hands on your belly.

INSTRUCTIONS

3. Breathe in slowly through your nose. Take the air into your belly and feel it blow up like a balloon.
4. Blow the air slowly out of your mouth through puckered lips. Feel your belly get small.
5. Do the exercise five times to practice. (Your child should do the exercise slowly 10 times until he/she gets his/her breath back.)

CHECK EACH PARENT TO SEE IF HE OR SHE IS DOING THE EXERCISE CORRECTLY.

SUMMARY

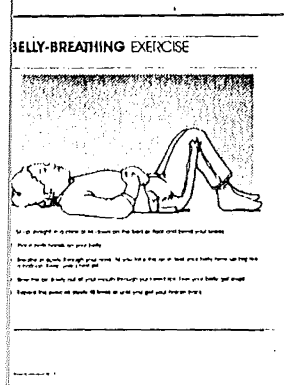
Belly breathing is a relaxation exercise that can be done anywhere to help children and parents stay calm during an attack. Belly breathing doesn't work for everyone, but it can have dramatic effects when it does work.

It can also be used to help your child take a breather during physical activities. Your children are learning the exercise today, too, so you can practice together.

DISTRIBUTE HANDOUT II.

Here's an instruction sheet on belly breathing you can use at home to help you remember how to do it. Try to practice at home this week by yourself in front of the mirror and with your child.

If your child has an asthma attack before the next session, practice belly breathing and see if it helps. We'll talk about how belly breathing has worked for you next time.



Tips For Teachers

- Make sure parents put their pocketbooks, packages, or sweaters out of the way so they can move freely when learning the exercise.
- Encourage everyone to try belly breathing. If parents seem reluctant, try to generate enthusiasm by saying how easy it is and how well it works.
- When demonstrating the exercise, exaggerate the expansion and contraction of the abdomen. Explain that by relaxing the muscles in the abdomen, the diaphragm above it drops, allowing the lungs above it to expand more fully with oxygen-rich air. Contracting the abdomen helps push air out of the lungs.
- If parents have trouble mastering the exercise, reassure them that many people do. Suggest that they practice at home where they will find their own breathing rhythm more easily in private.

HANDOUT 10

COMMON QUESTIONS ABOUT ASTHMA

What is asthma?

Asthma is a condition in which there is difficulty moving air in and out of the lungs, because:

Muscles around tubes to the lungs squeeze shut.

Mucus in the airways increases.

The walls of the airways swell.

How do you know when your child has asthma?

When the air has a hard time getting through, your child may:

Wheeze.

Have shortness of breath.

Cough.

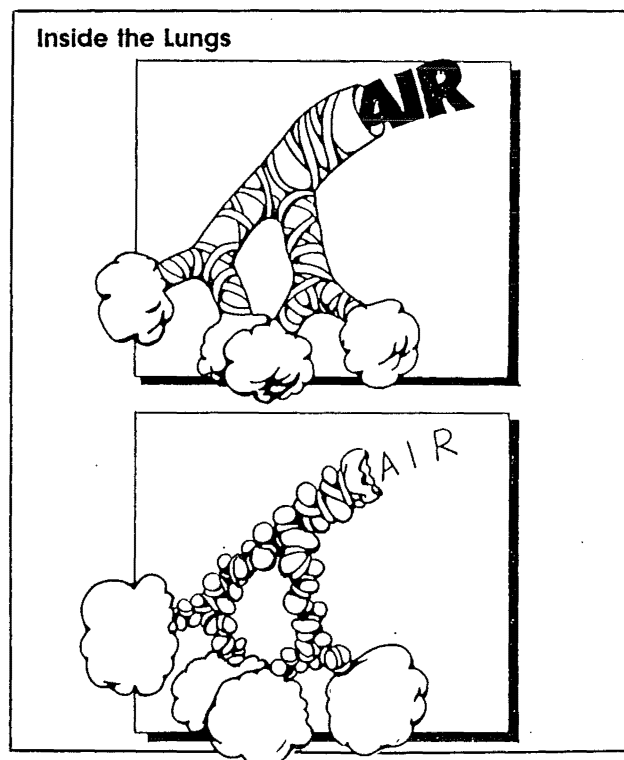
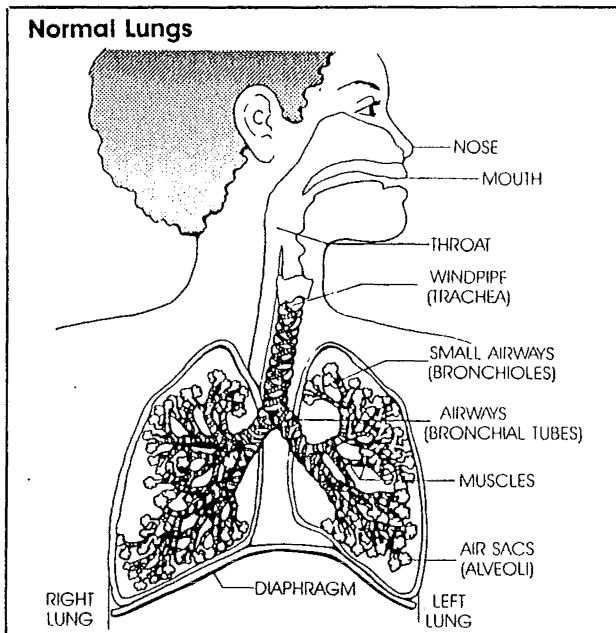
How did your child get asthma?

Some people are born with the possibility of developing asthma.

Of these people:

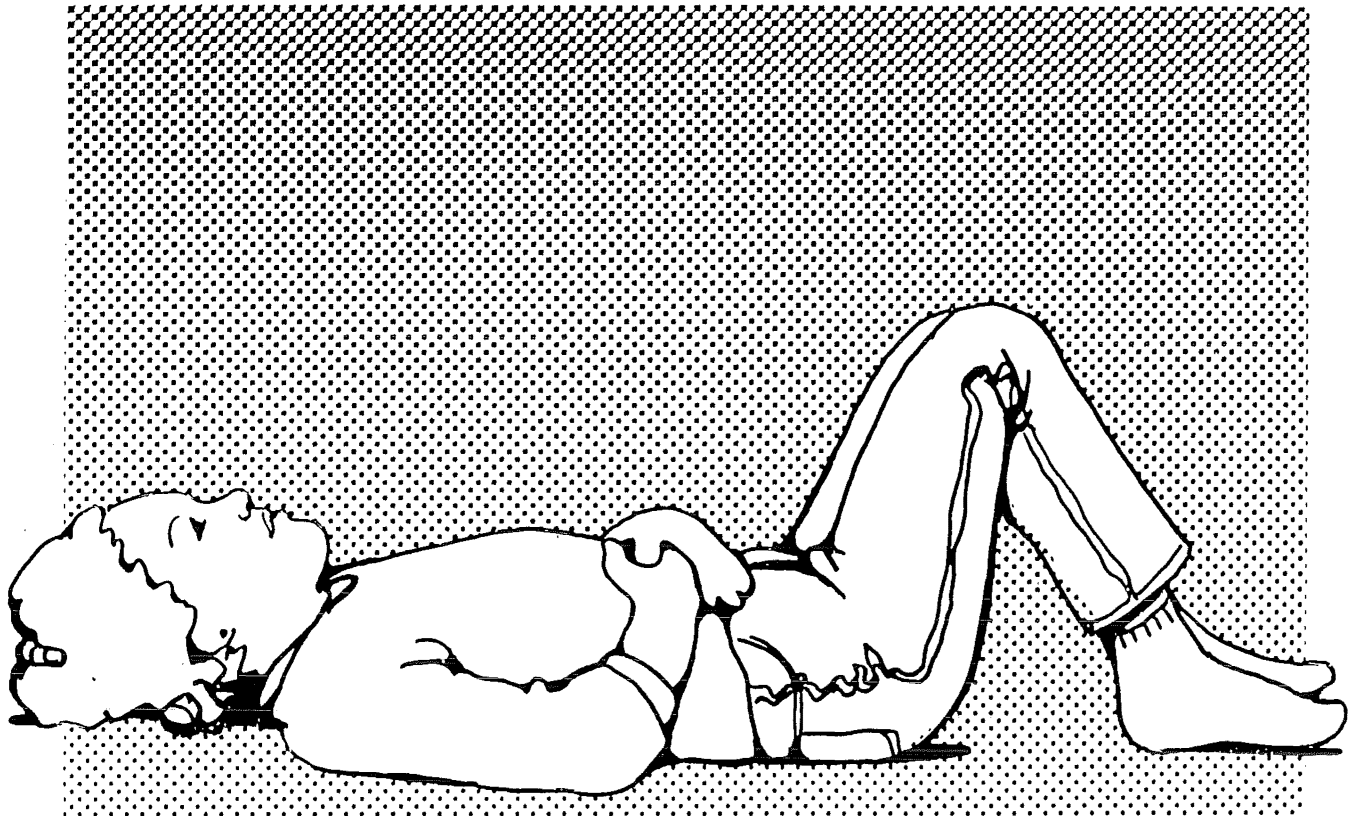
Some develop it.

Others do not.



HANDOUT 11

BELLY-BREATHING EXERCISE



1. Sit up straight in a chair or lie down on the bed or floor and bend your knees.
2. Place both hands on your belly.
3. Breathe in slowly through your nose. As you take the air in, feel your belly blow up big like a balloon. Keep your chest still.
4. Blow the air slowly out of your mouth through puckered lips. Feel your belly get small.
5. Repeat this exercise slowly 10 times or until you get your breath back.

PARENTS' SESSION TWO:

HOW TO HELP YOUR CHILD STAY ACTIVE

Topic: How to Help Your Child Stay Active

Purpose

To encourage parents to work with their children to establish guidelines for decisions about activities.

To encourage parents to discuss problems of wheezing after exercise with their doctors.

Objectives

Participants will:

- ❶ Express their values regarding regular exercise for children with asthma.
- ❷ Explore the idea that regular exercise is important for children with asthma.
- ❸ Recognize that wheezing with exercise is an indication that asthma is not under control and that this should be discussed with the doctor.
- ❹ Describe problems associated with regular exercise for children with asthma.
- ❺ Develop a set of guidelines they can use to help children safely increase the amount of exercise they get.

Process

Now we're going to talk about making decisions about the kinds of activities your child can do.

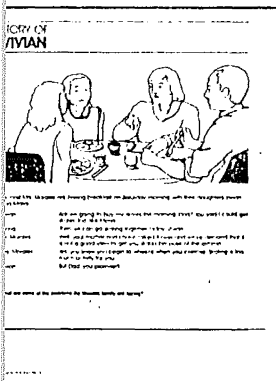
All parents want their children to grow and learn and be able to do the things they want to do. But, at the same time, parents want to protect their children so they don't get sick or hurt.

Parents of children with asthma especially feel this pressure. Some parents don't let their children get involved in enough activities because of their fears about asthma. Other parents let their children do too many things and they get asthma attacks.

Today we're going to talk about how parents can help their children stay active without getting asthma attacks. Here's a story about a family that is having a problem deciding about activities for their daughter who has asthma. Would anyone like to read it for us?

DISTRIBUTE HANDOUT 12 Read story if no one volunteers.

TALKING POINTS



STORY

Mr. and Mrs. Morales are having breakfast on Saturday morning with their daughters, Vivian and Maria.

- Vivian: Are we going to buy my skates this morning, Dad? You said I could get skates like Maria.
- Maria: Then we can go skating together today, Vivian.
- Mr. Morales: Well, your mother and I have talked it over and we've decided that it is not a good idea to get you skates because of the asthma.

Mrs. Morales: Yes, you know you begin to wheeze when you exercise. Skating is too much activity for you.

Vivian: But, Dad, you promised

ASK THE FOLLOWING QUESTIONS. Use the problems/solutions chart below to raise points participants don't suggest.

QUESTIONS TO
GENERATE
DISCUSSION

- What are some of the problems the Morales family is facing?
- Who is in conflict?
- What do you think Vivian is feeling?
- Has your child ever felt that way?
- What do you think Vivian's parents are feeling? Have any of you felt that way?
- What can Vivian's parents do to help her stay active without wheezing?
- What do you do?
- What can Vivian do to help herself?
- What does your child do?

ADDITION

Use the story of George (handout 7) in addition to the story of Vivian if there's time, or instead of it, if this scenario seems to have more relevance to your audience. You can use the same questions (with different names) as in the Vivian story and use the same problems/solutions chart as a reference.

Problems	Solutions
Parents are in conflict with each other and with the child about activities.	Talk about and make decisions on activities as a family. Work together toward setting fewer limits on what your child can do. Base decisions on: —What has actually happened with similar activities in the past. —The child's age. —The child's health. —The child's ability to accept responsibility and proven judgment in choosing activities. Don't base decisions on what you imagine or fear will happen.
Parents and child don't know what activities a child with asthma can safely do.	Let children test out activities if they've never tried them before. Let them demonstrate what they can do.
Children have problems with wheezing during an activity.	Have children improve their ability to do an activity by: —Practicing it. —Building up gradually on the time they can do it. —Using breathing exercises to control wheezing during the activity. Talk to the doctor to: —Adjust the medicine. —Get his help in finding an activity the child can do.

SUMMARY

Like all children, children with asthma need regular exercise. Most children can find some kind of exercise they can do without bad wheezing. Families need to work closely with each other and the doctor to find ways for children to exercise without wheezing. Let's review some of the ways to help your child stay active.

DISPLAY POSTER 7, DISTRIBUTE HANDOUT 13 AND REVIEW BASIC POINTS.

You can use this sheet to remind you about some of the guidelines we talked about for making good decisions about your child's activities.

Tips For Teachers

- This is a very difficult and challenging session for both parents and teacher.
- The teacher must be very careful not to evaluate or judge parents' behaviors related to decisions about the child's activities. It is very important to explore whether decisions are based on fear of what might happen or on actual experience.
- Other parents' experiences can be used to help participants see alternative ways of handling a decision about activities. By generating as many options as possible and a guide to the order of their use, parents may be able to increase their confidence in making decisions and decrease guilt associated with past restrictions.
- Rather than simply reinforcing the message that children with asthma should exercise regularly, the session encourages parents to seek ways actively and systematically to increase the child's activity level—with the help of the child, teacher, doctor, and/or others.

Activity: Tensing and Relaxing Exercise

Purpose

To introduce another relaxation technique.

To help parents understand how relaxation exercises can be used to take a breather from physical activities or to help stay calm during an asthma attack.

Objectives

Participants will:

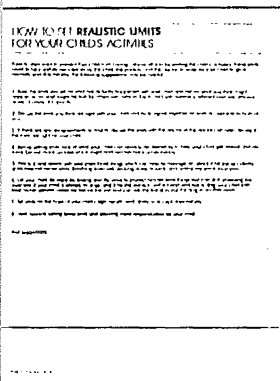
- ① Perform the tensing and relaxing exercise.
- Value the use of relaxation exercises to help children stay active.

Process

Now we're going to learn another exercise that you can do with children to keep calm and relaxed when managing asthma symptoms. It's called tensing and relaxing.

Tensing and Relaxing

1. Sit up straight on a chair or lie down comfortably on the bed or floor.
2. Place your hands on your legs or at your sides.
3. Close your eyes and drop your chin onto your chest.
4. Tense the top of your head as tight as you can. Hold it. Then relax it. Tense, hold, and then relax your: face, arms and hands, stomach, buttocks, legs, and feet.



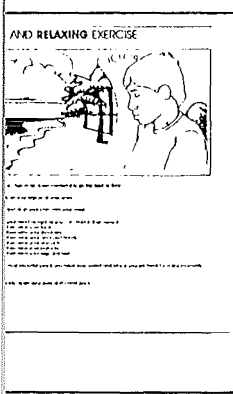
INSTRUCTIONS

5. Now think of the most beautiful place you have ever visited and place yourself there for a few moments. Relax.
6. When you are ready, open your eyes and come back.
7. Now shake each part of your body vigorously to wake up.

IMARY

Tensing and relaxing can help kids calm down and get their second wind during physical activity. By taking a breather during physical activity and doing a relaxation exercise, your child may be able to increase his or her activity level without wheezing.

Parents and kids can also use this exercise to keep calm during an asthma attack. Lots of people who don't have asthma do this exercise to improve concentration or rest for a few minutes during a busy day.



■DISTRIBUTE HANDOUT 14

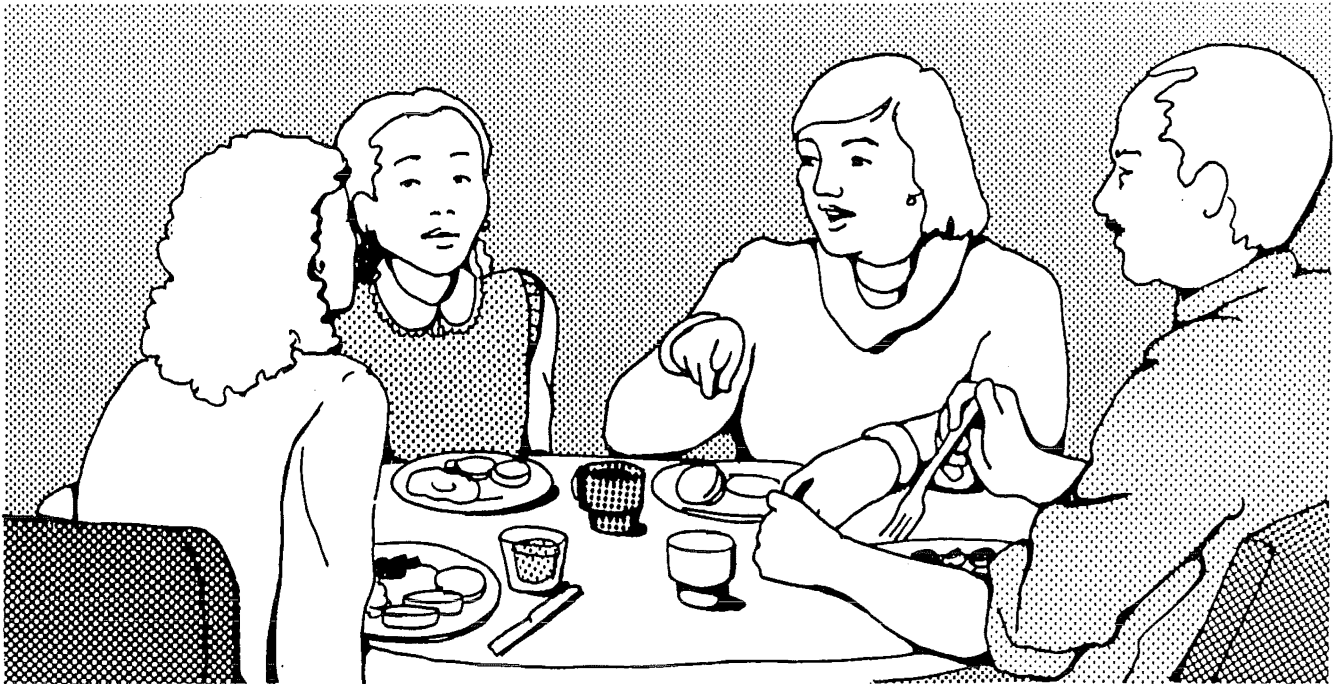
Here is an instruction sheet to help you remember how to practice tensing and relaxing at home.

Tips For Teachers

- Practice the exercise with someone else before you do it with a group of parents.
- Concentrate on keeping your voice calm and quiet.
- Speak slowly and give parents time to feel the difference between tense and relaxed muscles.
- Help parents to concentrate on the exercise by reminding them to keep their eyes closed.

HANDOUT 12

STORY OF VIVIAN



Mr. and Mrs. Lee
and Maria.

are having breakfast on Saturday morning with their daughters Vivian

Vivian:

Are we going to buy my skates this morning, Dad? You said I could get skates, too, like Maria.

Maria:

Then we can go skating together today, Vivian.

Mr. Morales:

Well, your mother and I have talked it over and we've decided that it is not a good idea to get you skates because of the asthma.

Mrs. Morales:

Yes, you know you begin to wheeze when you exercise. Skating is too much activity for you.

Vivian:

But Dad, you promised ...

What are some of the problems the Lee family are facing?

HANDOUT 13

HOW TO SET **REALISTIC LIMITS** FOR YOUR CHILD'S ACTIVITIES

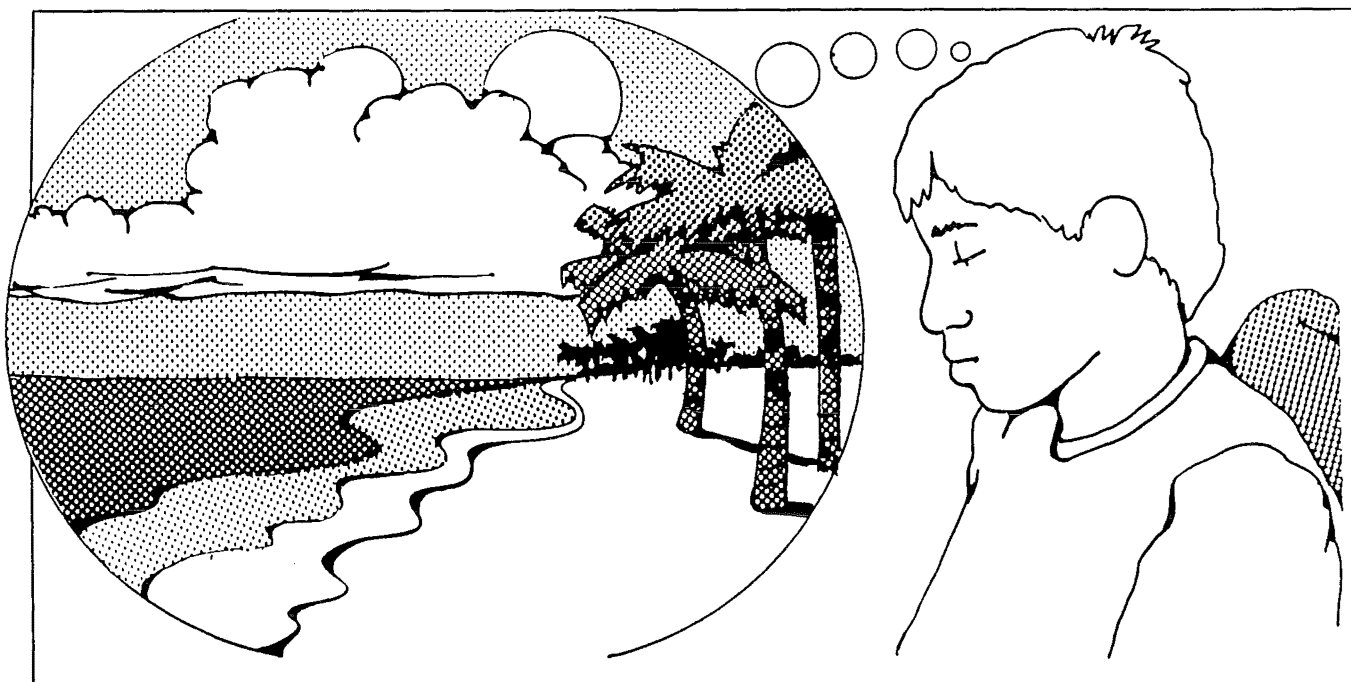
Parents often want to prevent their child from having asthma attacks by limiting the child's activities. These limits need to be carefully decided on by the child, the parents, and the doctor. In order for your child to grow normally and stay healthy, the following suggestions may be helpful.

1. Base the limits you set on what has actually happened with your child and not on what you think might happen or on what might be true for others with asthma. Each child with asthma is different and has different levels of physical capacity.
2. Discuss the limits you think are right with your child and try to agree together on limits acceptable to both of you.
3. If there are any disagreements or doubts, discuss the limits with the doctor so the doctor can help decide if the rules are right for your child.
4. Before setting limits, look at what your child can already do. Always try to help your child get ahead and do more. Do not make up rules which might hold him/her back unnecessarily.
5. Practice and review with your child those things which can help to manage an attack if he/she accidentally goes beyond his/her limits. Breathing exercises, drinking water or juice, and resting are some examples.
6. Let your child do more by finding specific ways to protect him/her from things that can start wheezing. For example, if your child is allergic to dogs, and if he/she wants to visit a friend who has a dog, your child can take his/her asthma medicine before the visit and can ask the friend to put the dog in another room.
7. Set limits on the basis of your child's age, health, and ability to accept responsibility.
8. Work towards setting fewer limits and allowing more responsibilities for your child.

Your suggestions _____

HANDOUT 14

TENSING AND **RELAXING** EXERCISE



1. Sit up straight on a chair or lie down comfortably on the bed or floor.
2. Place your hands on your legs or at your sides.
3. Close your eyes and drop your chin onto your chest.
4. Tense the top of your head as tight as you can. Hold it. Then relax it.
Tense, hold, and then relax your face.
Tense, hold, and then relax your shoulders.
Tense, hold, and then relax your arms and hands.
Tense, hold, and then relax your stomach.
Tense, hold, and then relax your buttocks.
Tense, hold, and then relax your legs and feet.
5. Now think of the most beautiful place you have ever visited and place yourself there for a few moments.
Relax.
6. When you are ready, open your eyes and come back.

PARENTS' SESSION THREE:

HOW TO MANAGE AN ASTHMA ATTACK AT HOME/ DECIDING WHEN TO GO TO THE DOCTOR

Topic: How to Manage an Asthma Attack at Home

Purpose

- To give parents ideas for actions they can take to manage an attack at home.
- To place a value on the preparedness and teamwork of parents and children in managing an asthma attack at home.
- To enable parents to make more accurate judgments about the necessity of medical treatment for an asthma attack.
- To build parents' confidence in their ability to manage an asthma attack.

Objectives

Participants will:

- ① List eight steps they can take to manage an asthma attack at home.
- ② Identify six appropriate criteria for deciding when it is necessary to seek medical attention for an asthma attack.
- ③ Consider the value of having a plan to manage an attack at home.
- ④ Discuss the usefulness of working as a team with the child to manage an asthma attack at home.

Process

Many of you have told us about the strong feelings you have when your child wheezes or has an asthma attack. We've already learned that one way to reduce fears about asthma attacks is to have more information about asthma. Another way is to do a relaxation exercise like belly breathing.

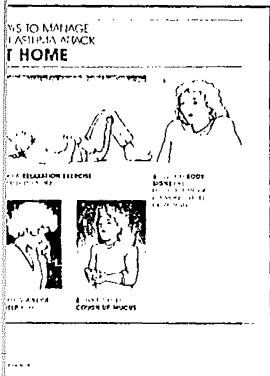
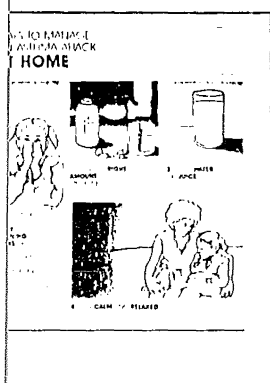
Today we're going to discuss how to reduce fears about asthma attacks by making a plan for managing an attack at home. With the plan, you'll learn what you and your child can do, working as a team, to take control of the attack. Knowing what to do makes everyone less afraid.

ASK THE FOLLOWING QUESTIONS. Use the eight steps for managing an attack at home (below) to correct misinformation and raise points not mentioned in discussion. Record suggestions on flipchart.

- What are some things you do right now when you see your child begin to wheeze?
- What does your child do?
- What else do you do?
- Why do you do that? Why is it important? How does it help?
- Which steps do you do first, second, etc.?
- What are your child's early warning signs of an asthma attack?

LINKING
INTS

QUESTIONS TO
GENERATE
DISCUSSION



Eight Steps to Manage an Asthma Attack at Home

1. Know what your child's early warning signs of an attack are (e.g., stuffy nose, tight chest, overtired feeling). That way, you and your child can begin to take care of it early.
2. Give the right amount of medicine at the right time. If your child has taken the prescribed medicine, do *not* give any more. If the doctor gave a second medicine to take during an attack, give it the way the doctor advised. Then wait for it to work. Don't give more than the doctor says to take.
3. Give some juice or water.
4. Stay calm and relaxed.
5. Have your child do a relaxation exercise like belly breathing. You can do it with your child.
6. Watch your child's body signs, like a hunched posture, how fast he or she is breathing, and how active the child feels like being. This will help you decide if a doctor's assistance is needed.
7. Call a family member, friend, or neighbor to help you.
8. Before and after the attack *ONLY* have your child cough and spit to bring up mucus. We'll learn to do this later in the session.

DISPLAY POSTERS 8A AND 8B TO REVIEW PLAN FOR MANAGING ATTACK. Distribute handout 15

We've come up with a lot of ideas for actions to take before and during an attack. These sheets will help you remember eight steps you can take to manage an attack at home. Let's go over them. Remember to go over the plan at home at a time when your child is not having an asthma attack.

Another problem parents often tell us about is trying to decide when to take the child to the doctor. They want to do the right thing, but they're not always sure if an attack is serious enough to need care at the doctor's office or emergency room.

Knowing when to get medical attention is part of managing an attack at home. We're going to read a story about some parents who aren't sure what to do. Then we'll try to come up with some guidelines to help them decide whether their son needs a doctor's help. Would any of you like to read the story for us?

DISTRIBUTE HANDOUT 16 Read the story if no one volunteers.

It is 12 midnight.

Mr. Armstrong: What's that noise? It sounds like Sammy is up.

Mrs. Armstrong: I'll go check on him. (She returns.) He's wheezing and coughing and complaining that he can't sleep.

Mr. Armstrong: What do you think we should do, take him to the emergency room?

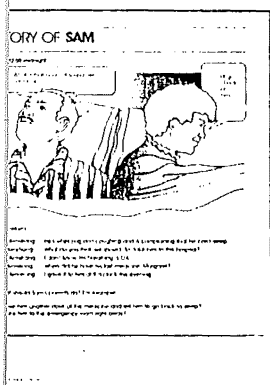
Mrs. Armstrong: I don't know. His breathing is okay.

Mr. Armstrong: When did he have his last medicine, Margaret?

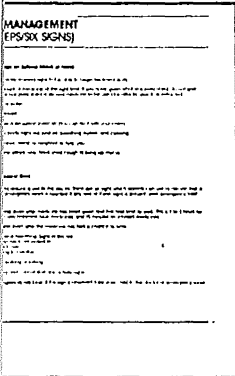
Mrs. Armstrong: I gave it to him at 9 o'clock tonight.

ALKING
DINTS

TORY



QUESTIONS TO GENERATE DISCUSSION



ASK THE FOLLOWING QUESTIONS. Use the six signs (below) to raise points not brought out in discussion.

- What decision should Sam's parents make?
- What led you to this conclusion?
- What evidence did you base your decision on?

Probable Participant Responses

- Give the child more medicine and send him back to bed.
- Take the child to the emergency ^{dept} room right away.
- Observe the child's body signs for change that would mean that the attack cannot be controlled at home.

Six Signs for Medical Care

Not all asthma attacks require a visit to the doctor. There are six signs which parents can use to decide that a trip to the doctor or emergency ^{dept} room is needed:

1. Wheezing gets worse even after medicine has been given and *has had time to work*. This is 1-3 hours for theophylline and catecholamine-type medicines, and 15 minutes for inhaled medicines, like Alupent or Ventolin.
2. Breathing gets faster even after the medicine has had a chance to work.
3. Child has a hard time breathing. Signs of this are:
 - Chest and neck are pulling in.
 - Child is hunched over.
 - Child is struggling to breathe.
4. Child has trouble walking or talking.
5. Child stops playing and cannot start any activity again.
6. Child's lips and fingernails are blue. If this sign occurs, take the child to the doctor or emergency ^{dept} room immediately.

DISPLAY POSTER 9. Review basic points.

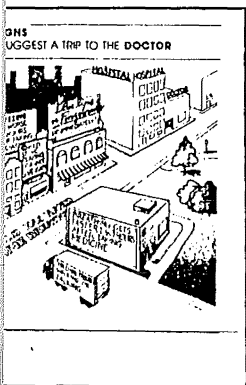
Following the eight steps for managing an attack and using the six signs for a trip to the doctor will help you and your children successfully handle asthma attacks at home.

Having this kind of plan will help you and your children be less afraid and panicked. You'll feel less anxious and more confident in your ability to deal with the situation.

Tips For Teachers

- Encourage parents to share the widest range of steps they can think of to manage an attack at home. Accept all steps as valid as long as they are not harmful.
- Some parents will respond that nothing can be done to manage an attack but rush to the doctor. Accept this feeling but emphasize that this is true only when attacks are sudden and severe. The strategy being developed can be used by most families to manage an attack at home and prevent an attack from becoming serious.
- When discussing guidelines for deciding when the child needs medical attention, accept idiosyncratic signs that parents use that apply to their child only. But emphasize the common signs that parents can recognize and agree on. Avoid long arguments over specific guidelines and move the process along.

SUMMARY



Activity: Belly Breathing, Productive Cough, and Massage

NOTE: CHILDREN JOIN PARENTS FOR THIS ACTIVITY

Purpose

To reinforce the idea that parents and children can work together to control asthma at home.

To let parents and children practice some of the eight steps when the child is not having an attack.

Objectives

Participants will:

- Consider the value of teamwork in managing an attack at home.
- Practice belly breathing, massage, and productive cough.

Process

INSTRUCTIONS

Since it takes teamwork between parents and children to manage an attack at home, the children are with us so we can practice some exercises as a team.

Would one of you kids like to help me show how to do belly breathing, massage, and productive cough as a team?

Belly breathing

Children, you'll do the belly-breathing exercise sitting down. Parents, stand behind your child and put your hand on his or her shoulders. Then do belly breathing the way we learned in session 1.

■ REVIEW INSTRUCTIONS ON P. 54 IF NECESSARY.

Massage

Parents, gently massage your child's shoulders, chest, and back. Rub gently in circular motions for several minutes until the child expresses relief or visibly relaxes. The purpose of massage is to have parents and kids work together to help each other relax.

Productive cough

■ GIVE EACH CHILD A TISSUE.

Children, first take a deep breath to open the lungs and airways. Second, cough strongly to bring up mucus from deep inside the lungs. Third, remove mucus with a tissue. This works well *early* when wheezing isn't severe. Don't do coughing in the middle of a serious attack. Do it early. You can even do this at school if you find a private place. Parents, encourage the child and make sure he/she takes a deep breath, then a big cough. Encourage children to cough up mucus, *not* just saliva in their mouth.

SUMMARY

We've seen that parents and children can work together to manage an attack at home by doing belly breathing, massage, and productive cough. Remember that belly breathing can help you relax during an asthma attack or as you take a breather during exercise. Massage can be used as an alternative form of relaxation if the belly breathing is not working well for the child. The massage can be done in association with productive cough. The sequence of these relaxation exercises is dependent on the personal preference of the child, based on past experience.

Remember also that productive cough is very helpful in getting rid of mucus. But only use it before or after an attack. Doing it during an attack will make the asthma worse.

In a later session (#6) we will be discussing the things that make kids wheeze. These are called triggers. In the meantime (before the next session), try to notice and remember the things that make your child have asthma symptoms.

I'd also like you to practice the team exercises we did today, both when things are fine and when kids are having an asthma attack, if one occurs. Next time, we'll talk about how they worked and hear your success stories.

Tips For Teachers

- Although it works well for parents and children to be together for this activity, each age group can meet separately if necessary. The teacher then plays the role of the parent in teaching children the team approach.

- Pair up parents with children. If one or the other is absent, pair participants with others who have absent partners. Try to have older children team up with younger ones when possible.

- Kids are often embarrassed when asked to cough up mucus. It is considered unsanitary and many parents have specifically instructed children not to do this. Emphasize to parents and children that coughing up mucus is very important if you have asthma. Give them permission to do it. Use yourself as a role model.

HANDOUT 15

ATTACK MANAGEMENT

(EIGHT STEPS/SIX SIGNS)

Eight Steps to Manage an Asthma Attack at Home

1. Know your child's early warning signs to be able to begin treatment early.
2. Give the right amount of medicine at the right time. If you have given what was prescribed, do not give more. If the doctor has prescribed a second medicine to be used for attacks, give it as instructed.
3. Give some juice or water.
4. Stay calm and relaxed.
5. Have your child do a relaxation exercise. (You can do it with your child.)
6. Watch your child's body signs like posture, breathing rhythm, and coloring.
7. Call a family member, friend, or neighbor to help you.
8. Before and after the attack only, have child cough to bring up mucus.

Six Signs to Seek Medical Care

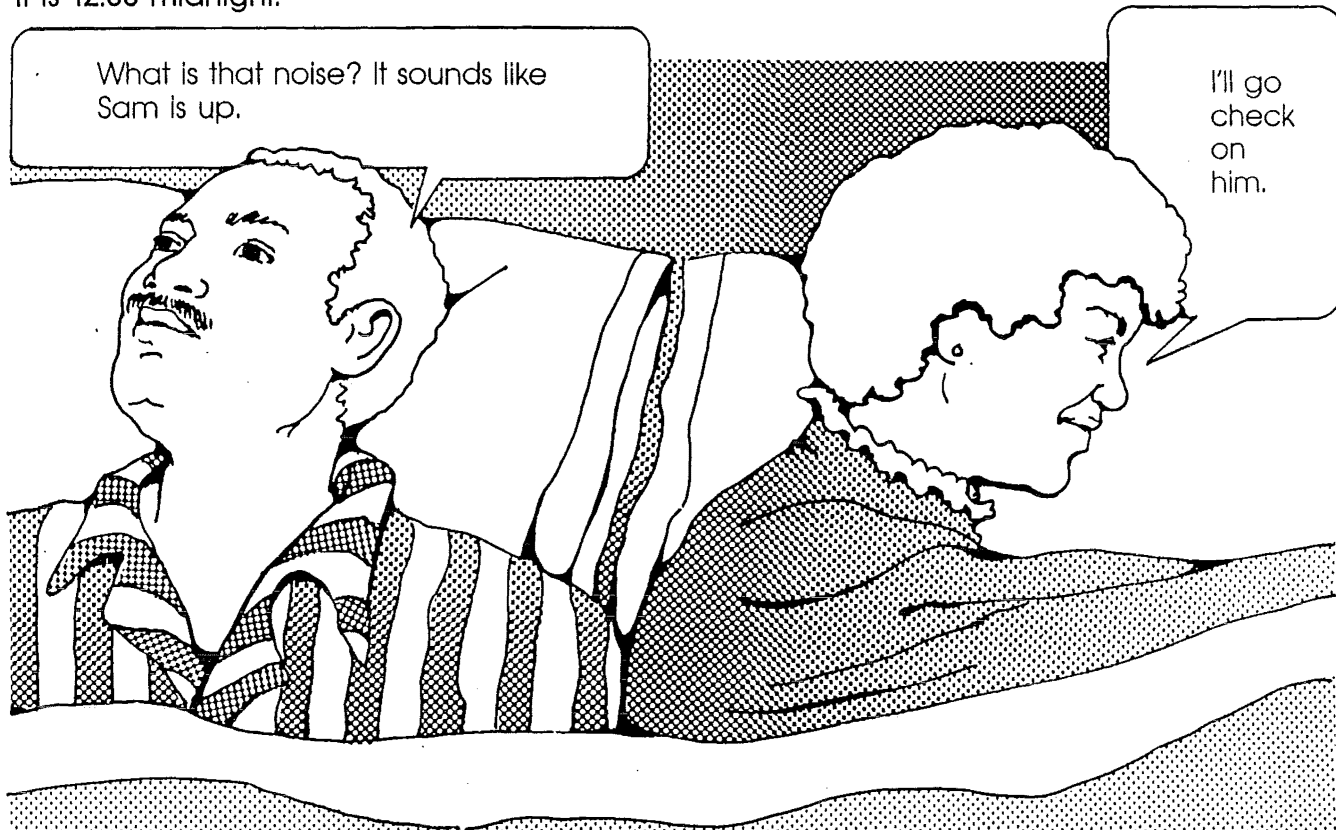
Not all asthma attacks require a visit to the doctor. There are six signs which parents can use to decide that a trip to the doctor or emergency room is needed. If any one of these signs is present, seek emergency treatment for your child.

1. Wheezing gets worse even after medicine has been given and has had time to work. This is 1 to 3 hours for theophylline and catecholamine type medicines, and 15 minutes for inhaled medicines.
2. Breathing gets faster even after the medicine has had a chance to work.
3. Child has a hard time breathing. Signs of this are:
 - child's chest and neck are pulled in;
 - child is hunched over;
 - child is struggling to breathe.
4. Child has trouble walking or talking.
5. Child stops playing and cannot start any activity again.
6. Child's lips and fingernails are blue. If this sign is observed, take your child to the doctor or emergency room **immediately**.

HANDOUT 16

STORY OF **SAM**

It is 12:00 midnight.



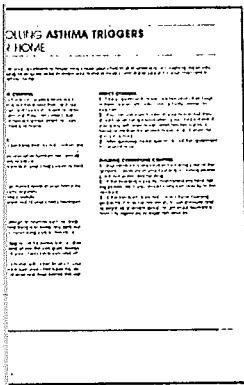
She returns.

- Mrs. Armstrong: He's wheezing and coughing and is complaining that he can't sleep.
Mr. Armstrong: What do you think we should do, take him to the hospital?
Mrs. Armstrong: I don't know. His breathing is O.K.
Mr. Armstrong: When did he have his last medicine, Margaret?
Mrs. Armstrong: I gave it to him at 9 o'clock this evening.

What should Sam's parents do? For example:

1. Give him another dose of the medicine and tell him to go back to sleep?
2. Take him to the emergency room right away?

PARENTS' SESSION FOUR:



Topic: Controlling Asthma Triggers in the Home

Purpose

To continue to promote parents' and children's feelings of confidence and success about managing asthma.

To enable families to discuss triggers to wheezing they found in the environment.

To assist families in finding ways to reduce triggers or remove their impact.

Objectives

Participants will:

- Analyze home situations to determine possible causes of wheezing.
- Discuss alternatives to reduce the impact of asthma triggers.
- Recognize how parents and children can work together as a team to reduce the triggers of asthma.
- Learn about service agencies that can be of help with housing/ environmental problems.

Process

Did anyone have an opportunity to try any steps to manage asthma at home? Can you tell us about it? How did you feel afterward? Did you try:

- Belly breathing?
- Massage?
- Productive cough?
- Taking medicine at first sign of symptoms?
- Discovering your early warning signs?

It is important to practice the things you have learned about managing asthma. Practicing the skills will help you feel more confident about taking care of asthma at home.

Today we are going to talk about things in the home that can cause or "trigger" asthma symptoms. Each person has different triggers, but some are common among many children with asthma.

LINKING
INTS

QUESTIONS TO GENERATE DISCUSSION

ASK THE FOLLOWING QUESTIONS. Write suggested triggers and ways to control them on the flipchart. Use the trigger/control list below to raise points participants don't make.

Did any of you look for things that cause your child to wheeze since last session?

Did you look both inside and outside your home?

What are your child's triggers for asthma?

What else?

Does anyone else have similar problems?

How do you help your child stay away from things that cause asthma symptoms?

Are some of the triggers hard to get rid of?

What do you do about it?

Does it help?

Common Asthma Triggers and How to Control Them

Trigger

Control

Dust and irritants
(cigarettes, aerosol
sprays, perfume, paint,
pollens)

Dust child's bedroom several times each week when the child isn't home, and air it out. Store infrequently used toys, books, etc., in closets and drawers. If they're left out they can collect dust. Don't use cigarettes, aerosol sprays, paint, or perfume when the child is around.

Feathers

Use pillows, bedding, and stuffed furniture with no feathers or kapok. Don't have stuffed animals in your child's bed or room.

Mold

Air out damp or humid rooms in your home regularly. Clean bathroom tile regularly. Don't put house plants in your child's room.

Pets
(dogs, cats, birds)

Don't have dogs, cats, or birds in the home. If you need a dog for protection or other reasons, limit the area where it goes. Keep pets out of your child's room and off his or her bed. Avoid long visits at homes where there are pets. When you do visit, be sure your child takes his or her asthma medicine at least 1 hour before the visit.

Insects
(some people with
asthma are allergic to
roaches as well as other
bugs)

Use insecticides to control them, but not when the child is at home. After spraying is done, air out the home for several hours.

Building conditions
(no heat, falling plaster,
broken elevators, refuse)

Ask the landlord to correct these problems. If he does not, it may be necessary to organize a tenant group or get legal assistance from city agencies.

HANDOUT 17

CONTROLLING **ASTHMA TRIGGERS** IN YOUR HOME

Certain things inside your apartment or house may cause your child to start wheezing or coughing, especially at night. The following list includes ways to make your home a more comfortable place for your child and to help control the asthma better.

DUST AND IRRITANT CONTROL

1. Dust your child's bedroom several times each week when she/he is not there and then air it out.
2. Store unused toys and books in closets or drawers. If you leave them out, they can collect dust.
3. Avoid the use of aerosol sprays, paint, or cigarettes when your child is at home.

FEATHER CONTROL

1. Use pillows and bedding that do not contain any feathers or kapok.
2. Stuffing in chairs and other furniture also should not contain feathers or kapok.
3. Avoid stuffed animals in your child's room or bed.

MOLD CONTROL

1. Get rid of damp, humid areas in your home by airing out such rooms regularly.
2. Clean bathrooms carefully.
3. Keep indoor plants out of your child's bedroom.

PET CONTROL

1. If your child is allergic to animals such as dogs, cats or birds, the best thing is to keep any pets out of your home. Also, avoid long visits to friends or family with pets.
2. If you need a dog or cat for protection or other reasons, limit the area where the pet goes. Always keep the pet out of your child's bedroom and off his/her bed.
3. When you visit a home with a pet to which your child is allergic, make sure your child takes his/her asthma medicine at least one hour before the visit.

INSECT CONTROL

1. Many apartments have roaches and other bugs in them; some asthmatics are actually allergic to roaches.
2. You can use insecticides in your home, but they should never be sprayed when your child is there. If you spray with insecticide, send him/her out to a friend or relative for several hours or do it when he/she is in school.
3. After spraying, make sure to air out the apartment for several hours.

BUILDING CONDITIONS CONTROL

1. Your landlord is responsible for taking care of the general conditions in your building, including plaster, paint, hot water and heating.
2. If the building is poorly maintained (no heat, falling plaster, etc.), you should complain directly to the landlord.
3. If the landlord does not correct these building problems, it may be necessary to use pressure and to organize a tenant group or get legal assistance from city agencies or legal aid services.

Your suggestions: _____

APPENDIX 3

COMBINATION INTERVENTION SESSIONS

The material presented to the Combination group was of the same content as that presented to the Compliance and Education groups. Sessions one and two of the Combination group covered material presented in the Compliance group's four sessions, whilst sessions three and four covered material presented to the Education group. However, due to the constraints of time, the amount of material able to be presented during the Combination group's actual session time was restricted. This necessitated the unpresented material being offered in a written format.

Detailed below are the materials which were presented to the Combination group in the written format. For an exact reproduction of all the material received by the Combination group, the reader is directed to the details contained within Appendices 1 and 2.

Combination group session 1: (Refer to Appendix 1, sessions 1 & 2)

The Combination group received the Handouts 1, 2, 3, 4, 5 & 6. These are as offered to the Compliance group. In addition, to compensate for reduced time in the Combination group's situation, this group was offered the following in written form: "Rationale for taking preventers" and "Medication usage" from session 1 (Appendix 1). "Stereotypes of doctors", "How we view them", "What makes a good / bad patient" and "Rights of the patient" from session 2 of Appendix 1. The remaining material from sessions 1 and 2 of Appendix 1 was presented to the Combination group within session times.

Combination group session 2: (Refer to Appendix 1, sessions 3 & 4)

The Combination group received Handouts 7, 8 and 9. In addition, they received the following sections in written form: "Meanings intended by your doctor", "Referral chart" and "memory and learning" from session 3 of Appendix 1 as well as "Tailoring" and "Asthma diary" from session 4 of Appendix 1. The remaining material in sessions 3 and 4 (Appendix 1) was presented to the Combination group within session time, as set out in Appendix 1.

Combination group sessions 3 and 4: (Refer to Appendix 2, sessions 1, 2, 3 and 4)

The material presented in these sessions was as set out in the Education group's four sessions. The single alteration was the deletion of material concerning basic information about asthma; this material was already covered in session 1 of the Combination group. As the emphasis with the Education material is on group discussion, rather than presentation by a facilitator, it was

possible to cover all material as set out in Appendix 2. This was achieved by limiting the time spent on discussion of topics during the Combination group's sessions.

Name _____

Age _____

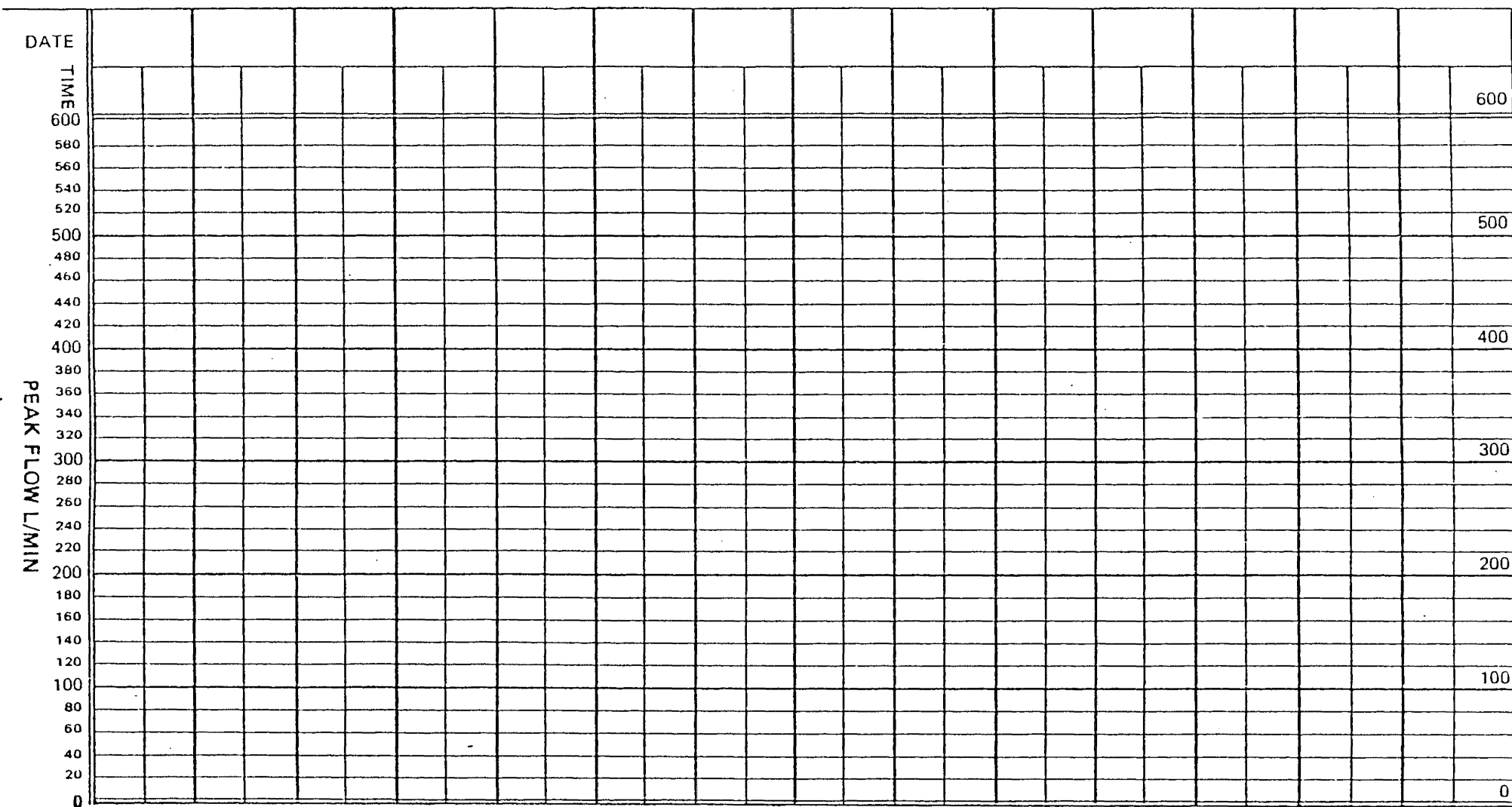
Sex _____

Drugs to be taken A _____

Drug Calendar Card

Drugs to be taken A _____

	Dry	wty	Time	Day of month
Morning				
Noon				
Afternoon				
Evening				



ON THE GRAPH — PLOT • FOR BEFORE BRONCHODILATOR

(JOIN DOTS ONLY •—•)

APPENDIX 6

ASTHMA INVENTORY FOR PARENTS

Part 1

Please circle the letter in front of the *best* answer to the following questions.

1. Steve is allergic to dogs. He should
 - A. not keep a dog.
 - B. keep his dog and take extra medicine.
 - C. only play with dogs at his friends' houses.
 - D. sleep with his dog in the same room to build up resistance.
2. Cold air makes Sandra wheeze. To help prevent asthma attacks she should
 - A. stay in the house all winter.
 - B. take more of her asthma medicine.
 - C. sleep with the windows open in the winter.
 - D. wear a scarf around her mouth and nose when it's cold.
3. Students who have asthma should
 - A. choose quiet, less active games.
 - B. avoid all sports because exercise causes coughing.
 - C. try to keep up with their friends when running laps.
 - D. do as much exercise as they can, but tell their P.E. teacher when they need to rest.
4. Angela has had asthma attacks when she gets upset. If other children tease her, she should
 - A. keep her feelings to herself.
 - B. pretend she's wheezing so they will quit teasing her.
 - C. talk about the problem with her teacher or her parents.
 - D. tell them she's going to have an asthma attack if they don't stop.
5. John's doctor gave him asthma medicine to take three times a day all year long. He should
 - A. take it at regular times when it is convenient.
 - B. take it only when he feels an attack coming on.
 - C. take it at regular times even if it is inconvenient.
 - D. take it at different times each day to build up resistance.
6. When John isn't having asthma symptoms, he should
 - A. relax and enjoy himself.
 - B. take his medicine less frequently.
 - C. take advantage of the opportunity to do such things as wash his dog or his friend's dog.
 - D. experiment with such things as foods or physical activities to find out which ones bring on an attack.
7. When your child has done the things that usually help and the wheezing and tightness are getting worse, he/she should
 - A. breathe quickly and shallowly.
 - B. let you know that he/she needs some help.
 - C. insist on going to the doctor immediately.
 - D. try a medicine that has worked well for a friend.

(continued)

8. Your child's prescription for asthma should be filled
- when it runs out.
 - before it runs out.
 - when he/she is really sick.
 - each time that he/she goes to the doctor.
9. In trying to control wheezing or asthma attacks, all of the following actions are okay for your child *EXCEPT*
- taking a hot shower.
 - drinking lots of water.
 - deciding to manage the attack on his/her own.
 - acting like his/her asthma problem doesn't exist.
0. When symptoms of asthma first start, it is a good idea for your child to
- call your doctor.
 - try to take it easy.
 - breathe rapidly to get more air.
 - take twice as many pills as usual.
1. Judy only has symptoms in the Autumn and Spring. She is probably allergic to
- grass.
 - animal fur.
 - rainy weather.
 - cigarette smoke.
2. John's doctor gave him an inhaler for his asthma. He should use it
- only at night.
 - three times every day.
 - only when he first starts to have symptoms.
 - according to the schedule his doctor gave him.

Part 2

Please circle the number corresponding to the word that best describes how frequently your child does each thing listed below.

	Never	Once in a while	About half of the time	Most of the time	Always
1. Stays away from things that cause breathing problems.	1	2	3	4	5
2. When having trouble breathing, gets away from what's causing it.	1	2	3	4	5
3. Does breathing exercises when having trouble breathing.	1	2	3	4	5
4. Tries to make self relax when having trouble breathing.	1	2	3	4	5
5. Tries to get mind off his/her breathing when starts to have breathing problems.	1	2	3	4	5

(continued)

	Never	Once in a while	About half of the time	Most of the time	Always
Tries something else when having trouble breathing and first treatment doesn't work.	1	2	3	4	5
Seeks help from other people at the first sign of breathing problems.	1	2	3	4	5
Lets friends talk him/her into doing things that could cause breathing problems.	1	2	3	4	5
Reports side effects of medicine to parents or physician.	1	2	3	4	5
Stays calm when having breathing problems.	1	2	3	4	5
Lets adults make him/her do things that could cause breathing problems.	1	2	3	4	5
Takes it easy the day following a night attack of asthma.	1	2	3	4	5
Tells friends that he/she has asthma.	1	2	3	4	5
Stops playing and takes it easy when having breathing problems.	1	2	3	4	5
Answer THIS QUESTION if your child is supposed to receive allergy shots.					
Forgets to get allergy shots on schedule.	1	2	3	4	5
Answer the THREE QUESTIONS below if the child has any prescribed asthma medications.					
Keeps asthma medicine handy at home, school, and when away from home.	1	2	3	4	5
Takes the correct medicine when breathing problems begin.	1	2	3	4	5
Takes the correct medicine on the prescribed schedule.	1	2	3	4	5

(continued)

Part 3

Please circle T (true) or F (false) to describe how you believe your child feels about asthma.

	True	False
1. Feels able to take care of his/her asthma.	T	F
2. Is embarrassed if other children know he/she has asthma.	T	F
3. Really hates having asthma.	T	F
4. Worries about having asthma.	T	F
5. Feels that asthma interferes with doing the things he/she wants to do.	T	F
6. Thinks that parents worry about his/her having an asthma attack.	T	F
7. Feels sad about having asthma.	T	F
8. Feels that people treat him/her better when he/she is having an asthma attack.	T	F
9. Feels that having asthma is his/her own fault.	T	F
10. Doesn't like having to take asthma medicine.	T	F
11. If teased about asthma, gets angry.	T	F
12. Feels it's important to tell teachers that he/she has asthma.	T	F

Part 4

Circle the number corresponding to the word that best describes how often the following things occur.

	Never	Once in a while	About half of the time	Most of the time	Always
1. I am very concerned about my child's asthma.	1	2	3	4	5
2. I avoid or soften disciplining my child because of the asthma.	1	2	3	4	5
3. Caring for my child's asthma is a drain on my time and/or energy.	1	2	3	4	5
4. I resent the fact that my child has asthma.	1	2	3	4	5
5. My child's asthma has been a cause of tension in our home.	1	2	3	4	5
6. My child's asthma interferes with the recreational and social activities of the family as a whole.	1	2	3	4	5
7. My child's asthma interrupts my own sleep and/or that of my spouse.	1	2	3	4	5
8. I am afraid to let my child do some things because of asthma.	1	2	3	4	5
9. My child's asthma interferes with our family's routine activities.	1	2	3	4	5

	Strongly Agree					Strongly Disagree	
	1	2	3	4	5	6	7
People can be helped a great deal by doctors.	1	2	3	4	5	6	7
Few diseases are totally crippling.	1	2	3	4	5	6	7
Getting well is often simply a matter of chance.	1	2	3	4	5	6	7
I have confidence in my own ability to cure myself when sick.	1	2	3	4	5	6	7
There is no such thing as bad luck involved in health.	1	2	3	4	5	6	7
Doctors actually relieve or manage to cure few health problems.	1	2	3	4	5	6	7
A person's good health is largely a matter of good fortune	1	2	3	4	5	6	7
Recovery from illness requires good medical care	1	2	3	4	5	6	7
Anyone is able to learn ways to prevent illness.	1	2	3	4	5	6	7
People staying well is totally unrelated to chance.	1	2	3	4	5	6	7
Doctors are rarely able to help sick people.	1	2	3	4	5	6	7
People who take care of themselves stay healthy.	1	2	3	4	5	6	7
Your recovery from an illness is not related to luck.	1	2	3	4	5	6	7
People cannot do much for themselves when they are sick.	1	2	3	4	5	6	7

	Strongly Agree					Strongly Disagree	
Doctors do not help patients to get well.	1	2	3	4	5	6	7
"Taking care of yourself" is unrelated to health.	1	2	3	4	5	6	7
Nothing can be done about some illnesses.	1	2	3	4	5	6	7
The seriousness of many diseases is overstated.	1	2	3	4	5	6	7
A person's poor health results from their own carelessness.	1	2	3	4	5	6	7
Doctors can do little to prevent illness.	1	2	3	4	5	6	7
At any stage, getting well is more a matter of chance.	1	2	3	4	5	6	7
Regular check-ups help us to stay healthy.	1	2	3	4	5	6	7
Some problems can be serious or even fatal.	1	2	3	4	5	6	7
Becoming sick is a person's own fault.	1	2	3	4	5	6	7
Doctors are able to help their patients feel better.	1	2	3	4	5	6	7
People who never get sick are just plain lucky.	1	2	3	4	5	6	7
Some diseases can just wipe you out.	1	2	3	4	5	6	7
There is little one can do to prevent illness.	1	2	3	4	5	6	7

Information About Child and Family

- A. Name of child _____
last / first / middle
- B. Your name _____
last / first / middle
- C. Relationship to child _____
- D. Child's date of birth _____ / _____ / _____
Day Month Year
- E. Sex _____(1) Male _____(2) Female
- F. Child's ethnic identity (optional)
_____(1) Asian _____(4) Pacific Islander
_____(2) Maori
_____(3) Caucasian _____(5) Other (specify: _____)
- G. _____ Number of brothers and sisters
- H. _____ Child's birth order (begin with "1" for first born)
- I. How many people live in the child's home? (List the relationship to the child and the age of each person who lives in the home. Include step-relations, family, friends, housekeeper, etc. Do not give names.) _____

Relationship to child	Age	Relationship to child	Age

____Total number of adults in home (16 and over)

____Total number of children in home under 16 (including subject)

- J.** Does the child share a bedroom with anyone else?

_____ (1) Yes _____ (2) No

(continued)

- K. Parents' occupations and levels of education. (List job titles and type of employer of parents or other persons who provide financial support for the child. **Circle** number corresponding to highest level of education for each person using codes in box below.)

Relationship to child	Job title and type of company	Education					
_____	_____	1	2	3	4	5	6
_____	_____	1	2	3	4	5	6
_____	_____						

1—less than fifth form

2—completed sixth/seventh form

3—Polytech or other

4—some university (not graduate)

5— university graduate (completed
Bachelors degree)
graduate degree (e.g., M.A., Ph.D., M.D.,
etc.)

Asthma History

- L. When was your child first treated by a doctor for asthma (i.e., wheezing and/or labored breathing that was *not* diagnosed as a cold, bronchitis, pneumonia, or other pulmonary disease)?

_____ year first treated for asthma

_____ age first treated

- M. When did your child first develop asthma symptoms (i.e., recurring episodes of labored breathing or wheezing)?

_____ year of first asthma symptoms

_____ age at first symptoms

- N. Do any of the child's close relatives have asthma? (List relationship to child; do not give names.)

Information About Home Environment

1. Does anyone smoke at home? _____(1) Yes _____(2) No

2. If "yes," how many smoke at home? _____

3. Does the family have any furry pets? if so, do they stay in or outdoors?

_____ (1) No furry pets

_____ (3) Yes, kept indoors occasionally or always

_____ (2) Yes, kept outdoors only

(continued)

If the child's bedroom has a carpet, what type of pad is under the carpet?

____(1) Jute or felt

____(3) Don't know

____(2) Synthetic or other than jute or felt

What type of mattress does the child sleep on?

____(1) Cotton batting

____(4) Kapok without cover

____(2) Spring & synthetic construction
(polyester)

____(5) Other

____(3) Foam without cover

____(6) Don't know

What type of pillow does the child use?

____(1) Synthetic

____(3) None

____(2) Down or feather

____(4) Don't know

What type of blanket, comforter, or quilt is on the child's bed?

____(1) Synthetic material

____(3) Other material

____(2) Wool or down

____(4) Don't know

Are there any stuffed animals in the child's room?

_____ (1) Yes _____ (2) No

Are there any houseplants in the child's room?

_____ (1) Yes _____ (2) No

rent Asthma Problems

About how often did your child have an *asthma attack* during the last 3 months? An asthma attack is any time when your child reported asthma-related discomfort such as wheezing and chest tightness. (Check one)

_____ (1) No attacks in last 3 months _____ (5) About 12 times

____(2) Only once or twice

____(6) Several times each week for the last 3 months

____(3) About three times

____(7) Nearly every day for the last 3 months

____(4) Six to nine times

How many days did your child miss from school because of asthma during the last 3 months?

_____ + _____ (enter "0" if none)

Full
Days

Half Days

How many days did your child spend in bed because of asthma during the last 3 *months*?

_____ + _____ (enter "0" if none)

Full
Days

Half Days

(continued)

i. Does asthma limit the kinds of things your child can do?

_____ (1) No _____ (2) Yes

l. If "yes," indicate areas of the child's life that are restricted or in some way affected by asthma:

_____ (1) Diet	_____ (6) Furnishings in room
_____ (2) Exercise and sports	_____ (7) Travel or vacation
_____ (3) Social activities	_____ (8) Work (chores, part-time job, etc.)
_____ (4) Schoolwork	_____ (9) Sleep
_____ (5) Having pets	_____ (10) Other (specify: _____)

m. What kind of P.E. program does your child have? (Check one)

_____ (1) Regular P.E.
 _____ (2) Limited P.E. or special classes
 _____ (3) P.E. is not required or offered at child's school
 _____ (4) No P.E. because of asthma

Current Asthma Treatment

n. Is your child now taking any medicine for asthma, including over-the-counter drugs or nebulizers?

_____ (1) Yes _____ (2) No

o. If "yes," what medicines and on what schedule?

Name or type of drug **How often taken** (number times per day)*

_____	_____
_____	_____
_____	_____
_____	_____

child is to take medicine only when having symptoms, write "as needed."

p. Is your child receiving allergy injections? (Check one)

_____ (1) Yes _____ (2) No

If "yes," how often? (Check one)

_____ (1) Every other week or less _____ (3) Twice per week
 _____ (2) Once per week

If "yes," what time of year? (Check one)

_____ (1) Autumn _____ (4) Summer
 _____ (2) Winter _____ (5) All year round
 _____ (3) Spring

(continued)

If you know, check the substances or groups of substances to which your child is allergic.

- | | | |
|----------------------------|----------------------|-----------------------------|
| ____(1) Grass pollens | ____(8) Cattle hair | ____(15) Housedust |
| ____(2) Weed pollens | ____(9) Horse hair | ____(16) Molds |
| ____(3) Tree pollens | ____(10) Rabbit hair | ____(17) Drugs |
| ____(4) Cotton linters | ____(11) Hemp | (specify: _____) |
| ____(5) Feathers and down | ____(12) Kapok | ____(18) Foods |
| ____(6) Cat hair | ____(13) Wool | (specify: _____) |
| ____(7) Dog hair | ____(14) Jute | ____(19) No known allergies |

Have any of these substances caused your child to have an **asthma attack*** in the past?

- ____(1) No
 ____ (2) Yes
 ____ (3) Don't know

*An "asthma attack" is an episode of labored breathing requiring medical treatment and/or medication.

Tick any of the following that have caused your child to have an asthma attack.

- | | |
|---|--|
| ____(1) Smoke, fumes, or air pollution | ____(5) Anger |
| ____(2) Hot, cold, or damp weather, or
change in weather | ____(6) Excitement or laughing |
| ____(3) Physical activity | ____(7) A cold or infection |
| ____(4) Fear or worry | ____(8) Some other reason(s)
(specify: _____) |

e of Medical Facilities

Was your child hospitalized for asthma or breathing problems during the last *3 months*?

- ____(1) No ____ (2) Yes

If "yes," how many times and how long each time?

____ Number of hospitalizations

1st hospitalization: ____Days 3rd hospitalization: ____Days

2nd hospitalization: ____Days

How many times did your child see a Doctor because of asthma or breathing problems during the last *3 months*? (Do not count hospitalizations listed above or visits for allergy shots only.)

____ Number of Doctor visits

If any Doctor visits, by whom was the child seen?

- | | |
|---------------------------------------|--|
| ____ Pediatrician or family physician | ____ Emergency room or emergency clinic physician |
| ____ Allergist | ____ Other physician, e.g., pulmonary specialist
(specify: _____) |

If any Doctor visits, how many required emergency treatment (i.e., a shot of epinephrine or something similar; intravenous aminophylline, hydrocortisone or other steroid; IPPB with bronchodilator)?

____ Number of emergency visits

PART A

	Disagree strongly				Agree strongly		
My attitudes and beliefs concerning asthma have changed over the last 3 months.	-3	-2	-1	0	1	2	3
I feel more confident in handling my child's asthma after this study.	-3	-2	-1	0	1	2	3
My knowledge concerning asthma has improved.	-3	-2	-1	0	1	2	3
My ability to give medication correctly, as prescribed, has increased.	-3	-2	-1	0	1	2	3
The health of my child during the last 3 months has improved.	-3	-2	-1	0	1	2	3
Taking part in this study has been of benefit to myself and our family.	-3	-2	-1	0	1	2	3
Such a programme would have been of benefit when my child was first diagnosed as asthmatic.	-3	-2	-1	0	1	2	3
I feel more able to discuss asthma, and clarify problems with my doctor, since taking part in this study.	-3	-2	-1	0	1	2	3

PART B

Please give your honest impressions in a paragraph (or longer if you wish) to the following questions.

- 1) Have there been any specific changes over the last three months in the way that you handle asthma and its problems?

PARENT/GUARDIAN INFORMATION SHEET

Asthma is a chronic illness where inadequate control can seriously interfere with a child's quality of life. Medication can both prevent and control asthmatic episodes, however, it can only be effective if the sufferer uses it correctly. It appears that anything up to 93% of asthmatics make mistakes regarding the use of their medicines. The major reasons for this appear to be :

- a) Problems in understanding instructions
- b) errors in administering the medicine

It is felt that a programme which can increase comprehension and eliminate these errors would benefit both parents and the child sufferers. We feel that education packages and assistance in ensuring correct administration may be of possible help with this problem. The aim of the study is to establish that these procedures increase your ability to use the medicines as your child's doctor has prescribed.

If you choose to be part of this study, you and your child will be asked to complete some tasks throughout the study. For example, before the study begins, then again at the end, we will ask you to complete three questionnaires. The first deals with general knowledge about asthma, the second with your child's illnesses over the previous three months and finally one to do with your thoughts about health.

Once the study begins, you will be asked to attend four one hour sessions, one per week, where information will be provided and discussed. The programme is designed to teach you (and possibly your child) information and skills about asthma, which will increase both knowledge and correct administration of medicine. Each session will deal with a specific area of asthma so that the four sessions will combine into a complete programme. You will be provided with knowledge and skills which you can use in your own home to help you better understand and control your child's asthma.

The format will be one of group learning and discussion. The other group members (up to ten) will be parents who face similar difficulties as your own family. Each parent will have the opportunity to express his/her own feelings as well as contribute to the programme if they so desire. For each session a variety of written material will be distributed so that parents may have the opportunity to read over the material presented after the sessions end.

During this time, and at various times over the following three months, you will be asked to record information about your child's medicines. Each day we would like you to note down the amount and type of pills your child took, his/her performance on the peak-flow meter plus when s/he used the bronchodilator. You will be given all the necessary sheets to record this information on.

In addition, we would like your permission for access to your child's medical records. This is so we can have information about your child's past medical history. Any information collected by the researchers involved in this study will remain confidential to the investigators.

PARENT/GUARDIAN CONSENT FORM.

1) I, _____, have read the attached information sheet and fully understand the procedures involved. I have also had explained to me the expectations of both my child and myself.

2) I have discussed this with my child and s/he is willing to participate .

3) I understand that I will be involved in completing three questionnaires and the recording of information about my child's medication.

4) I realize that my involvement in the programme will require attendance at four consecutive group sessions, each lasting one hour. These sessions will be held once a week.

5) If at any time I have any concerns or wish to have something explained , I am free to discuss these areas with the researchers .

6) I give my full permission to make my child's hospital files available to the researchers . I understand that such access and the information involved will remain completely confidential .

7) I understand that I am able to withdraw completely from this study at any stage, without it affecting my child's access to treatment in the hospital.

Signed

Date

Witnessed by

Date
